The Long and Winding Road: My Journey in Diabetes Education

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Editor’s note: This article is adapted from the address Dr. Siminerio delivered as the recipient of the American Diabetes Association’s Outstanding Educator in Diabetes Award for 2011. She delivered the address in June 2011 at the association’s 71st Annual Meeting and Scientific Sessions in San Diego, Calif.

I am honored to represent the work of diabetes education, accomplished by me in small part and by many colleagues, and I am privileged to recognize the impact that our work has had on people with diabetes.

When I got news of this award, I wanted my presentation to be tied to a theme that captured my passion and one with which a wide audience could identify. The music of The Beatles is expressive and shared across all cultures, so Beatles music it was. The Beatles song that generates emotion and illustrates the course of diabetes education for me is “The Long and Winding Road.”

The Journey Begins

Allow me to rewind to the 1960s, when I was a young girl infatuated with The Beatles and, coincidentally, when I was introduced to diabetes.

My father, John (Figure 1), was a World War II veteran who, like many other young Americans back then, believed the only way ahead was through education. He had dreams of being a psychiatrist, but becoming a physician was not in his cards.

At the age of 30, he was diagnosed with type 1 diabetes during the one-shot-a-day-and-no-monitoring era. No education, no team care. The science of diabetes was embryonic, and the health care system in the 1960s failed him. He died at the age of 52, a quadriplegic from a series of strokes. Today, my brother fights another kind of battle with chronic disease. Unlike our father, he has the advantages of new drug therapies and a mental health team.

When I told him about this talk, he said, “Lin, make sure you tell them that without my team I wouldn’t have hope.” This presentation is dedicated to my father and brother, my reasons for staying the course.

On my father’s first day home from the hospital after diagnosis, he had a hypoglycemic seizure. No one had taught him about symptoms or treatment of low blood glucose. That experience sparked my commitment to education. I went off to college, and the pressure was on. My father had projected his unmet goal to become a physician onto me. How disappointed he was when I chose nursing. I remember him saying, “I doubt that you can influence change as a nurse,” and asking if I thought...
I was really suited to taking orders from a doctor.

My Education on the Importance of Education
I took my first job at Children’s Hospital in Pittsburgh, Pa., where I met my first patient with diabetes, an 11-month-old boy named Jerod (Figure 2). His parents were at their wits’ end when they sought advice for their sick baby and were repeatedly told he simply had the flu. His glucose levels rose so high that it blocked the blood flow to his legs. Both legs were amputated at a small, rural hospital before he was admitted to Children’s.

Figure 2. Jerod, the author’s first patient with diabetes.

Jerod’s experience left an indelible mark on me. I realized that there was a pathetic lack of education for people with diabetes and their families.

Fortunately, the 1970s brought an education awakening, when diabetes visionaries began paving the way toward creation of diabetes care teams. I was lucky enough to be at Children’s with Dr. Allan Drash and to become one of the first pediatric diabetes educators.

Our team at Children’s was encouraging and supportive. So, when I had an idea to start a camp in western Pennsylvania and to bring along some faculty, fellows, and staff members, they agreed and joined me as camp volunteers.

Knowledge Alone Is Not Enough
Blood glucose monitoring arrived on the scene soon after we started our camp. What a relief, not only for our patients but for all of my camp colleagues. Gone were the days of setting up mini-laboratories for urine testing in those outhouses and making night rounds when the only way to detect hypoglycemia was by feeling the children’s foreheads for perspiration.

In those early days of blood testing, you almost needed an engineering degree to simply calibrate the machine. Still, this new tool was heralded as the key to preventing diabetes complications.

Despite the early hoopla, however, the 1986 American Diabetes Association (ADA) consensus report on self-monitoring of blood glucose was disappointing. Glucose control did not improve. We were advised to advance the technology to improve accuracy and to establish algorithms. And the diabetes community was reminded in no uncertain terms that patients require education to self-regulate their glycemic control.

Industry responded by improving blood glucose meters. But more than 20 years later, another report offered messages that were much the same as in 1986: blood glucose monitoring results are meaningless if people don’t learn how to react to their numbers.

Growing Pains
We were just beginning to get some traction on our education journey when we experienced another twist in the road: the 1980s brought criticism to the emerging field of diabetes education. In a frequently cited, randomized, controlled trial, investigators reported that education may not be efficacious for adults with diabetes.

Although this was discouraging, the education community gleaned an important message. In this large group of patients who received education compared to those in usual care, knowledge scores improved, but clinical measures such as A1C did not.

Of course, we should have known that simply improving knowledge would not be enough to change behaviors and outcomes. As the investigators from another study nicely summarized, “The effects of educational programs are of limited value if they do not lead to permanent changes in attitudes and motivation.”

This triggered a change of direction: measures of successful education should not be limited to improvements in knowledge and A1C levels. When we think of improvements related to education, we need to consider an outcomes continuum (Figure 3). Knowledge leads to behavior change that can lead to improvements in clinical outcomes such as A1C and long-term outcomes such as reductions in cardiovascular disease.

The DCCT: Validation and More Challenges
Fortunately, the Diabetes Control and Complications Trial (DCCT)
came on the heels of these studies, and I had the opportunity to work with the Pittsburgh DCCT team. At long last, the DCCT provided the evidence for glycemic control and reaffirmed the work of the multidisciplinary health care professionals who made the trial’s intensive therapy intervention happen.

Before the DCCT, skills such as medication management were solely the responsibility of physicians. But DCCT team members representing the fields of nutrition and nursing reported on their trial experience. There was a need to expand the roles of these professionals to translate the trial results into real-life clinical practice. This, certainly, was a bright spot along the road.

But, yet again, there were challenges. Headlines appeared, such as one from the New York Times reading, “Programs to Cut Risks of Diabetes Surprisingly Fails to Lure Patients.” The diabetes care community was slow to adopt the message of the importance of intensified therapy. Why? Most likely because we did not have the systems organized and the necessary tools available to replicate the brilliant yet rigorous efforts of the DCCT investigators.

**When in Doubt, Research!**

These controversies and questions ignited the interests of some forward-thinking people. Behavioral scientists and educators directed their efforts to the study of behavior and practice change. Their research addressed uncharted territory at the time, including depression and diabetes, family involvement, patient-centered approaches, measurement approaches, health literacy, nutrition therapy, and peer support. Findings from their research were changing attitudes toward patients and practice.

While these ideas were starting to percolate, I was somewhat stuck on my personal journey as an educator. One of my campers had a severe hypoglycemic event in college that left her with many limitations. We needed to better understand how to help our young patients in transition from childhood to adult life, from pediatric to adult health care. I needed a new course; maybe I could study such problems.

**Rewarding Results**

One of the early large studies I worked on was the Diabetes Attitudes, Wishes, and Needs project. DAWN was designed to explore the attitudes, wishes, and needs of patients, physicians, and nurses in 11 countries. We uncovered a number of disturbing issues that were plaguing people with diabetes: poor self-management and quality of life, poor glycemic control, severe complications, and widespread disability and depression.

We learned that there was a global gap between the psychosocial needs of people with diabetes and the support available to them from health care systems.

The results were used to provide insights on a number of patient and practice behaviors. For example, we were able to reaffirm the role of nurses. Nurses reported that they provided feelings of hope, discussed compliance, acted as an intermediary, and talked to families. In short, nurses helped to address the psychosocial needs of patients, an area that is crucially important in disease management.

And in this same study, when patients reported having access to someone such as a nurse, they had better outcomes. Unfortunately, we also found that less than half of the patients surveyed had available nursing services and that nurses had little involvement in medication management and limited scopes of practice.

But were nurses willing to take on more responsibility? Nurses did report willingness to take on more responsibility and to do more with additional training. As we move forward on the long road of health care reform for which the aim is better access to quality care with lower costs, we need to capitalize on this willingness and opportunity.

This is especially true given that the physicians who participated in the study agreed that we need better communication and more access to psychologists and qualified nurse educators and specialist nurses. Overwhelmed with a growing patient population with chronic diseases, physicians are welcoming support.

In a narrative review, Davidson summarized his findings regarding the roles of nurses and pharmacists. In randomized clinical trials, A1C levels were lowered approximately three times as much by nurses or pharmacists following detailed treatment algorithms under the supervision of a physician than through usual care. Given the diabetes epidemic, our medical care system should strongly consider this approach to improving diabetes care.

Other studies reaffirmed these messages. Meta-analyses such as one by Shojania et al. showed that the best predictors of improved glycemia are team changes and case management.

Investigators were also exploring the effectiveness of diabetes education on clinical outcomes. The review most often referred to is the publication by Norris et al. summarizing the effects of diabetes self-management education (DSME) for patients with type 2 diabetes. These researchers found that DSME is associated with a dramatic decline in A1C by as much as 0.76% and that the effectiveness of DSME was directly correlated to the amount of time patients spent with an educator. However, as with most therapies, the benefits of education decrease without continued doses (educator contact). The take-home message: sustained improvement requires both time and follow-up, what we now refer to as “self-management support.”

Other investigators looked at cost savings. For example, in an evaluation of the association of educational visits with hospital admission rates and charges for diabetic patients in eight Philadelphia Health Centers, no education was associated with the highest hospitalization rate and costs, whereas nutritionist visits were most strongly associated with reduced hospitalizations and a substantial reduction in hospital charges. This suggests that providing educational services, particularly in the area of nutrition, may be highly cost-effective.
Although many of these findings appear intuitive, we needed, as a discipline, to build the evidence base. To summarize, we have learned that education is effective and cost-saving, but that the benefits of education decrease over time and require ongoing therapy. We also now have the evidence that team-based care is the best predictor of improved glycemia and that effective communication is key. And finally, we know that, when patients have access to education or nursing-like services, outcomes are better, but, sadly, these services are often unavailable.

Along with a surge in research, organizational changes were also happening throughout the 1980s and ’90s. Trailblazers used the mounting evidence to put education on the diabetes road map. They helped to integrate education into their diabetes clinical care practices and gained prominence in national organizations such as the American Association of Diabetes Educators (AADE), the National Diabetes Education Program, ADA, the Centers for Disease Control and Prevention (CDC), and the American Dietetic Association Diabetes Care & Education Practice Group. These pioneers established standards, fought for insurance reimbursement, and took key leadership positions in our national organizations.

PRIDE: Bringing It Home to Pennsylvania

And as the field of diabetes education earned increasing prominence, I was home in Pittsburgh thinking about how I and my colleagues at the University of Pittsburgh could take all we had learned from our academic hub to rural communities where people live who often are among those hardest hit by chronic disease.

My colleagues and I started our projects in 2000, when we made our first attempts at addressing the Healthy People 2010 education objective: that at least 60% of all people with diabetes would receive diabetes education. As shown in Figure 4, accomplishing this for rural communities would be particularly challenging.

Because Pennsylvania has the third-largest rural population in the United States, accounting for ~30% of our population, we had our work cut out for us. We received funding from a variety of sources, including various foundations, the Pennsylvania Department of Health, industry, and a large award from the U.S. Department of Defense to study care practices.

I was introduced to the chronic care model (CCM), a health care delivery approach that many communities are using as a framework for improvements in chronic care. The model was particularly appealing to me because the pillar of the model was an informed activated patient and a prepared practice team, all dependent on a number of overlapping elements, including community resources and policies, self-management support, delivery system design, decision support, and information systems.

Assessing access

We started by asking, “Are we reaching people?” The hospitals and practices of the University of Pittsburgh Medical Center (UPMC) provide diabetes care for >180,000 people in the region. We examined a cohort of 12,745 patients from the UPMC diabetes database during a specific timeframe and found that only 12% had received DSME, no one had participated in medical nutrition therapy (MNT) alone, only 5% had received both DSME and MNT, and a disappointing 83% had received neither DSME nor MNT.

We then examined services in one of our rural communities where we have an ADA-recognized education program that is familiar to all of the local providers. We reviewed records of 295 of their patients with type 2 diabetes and found that 162 patients (65%) had never received any education services. Despite efforts to improve awareness of education services, 76% of those patients who had not received education services had never even received a referral for education. Interestingly, 83% of the patients who did receive a referral attended the education program.

Sadly, many of the 162 patients who never received education were at high risk for complications; 17% were smokers, 85% had hypertension, 78% had hyperlipidemia, 65% were obese, and 92% had more than two of these risk factors. And when were these patients referred to education? Apparently, when all else failed. Patients having the most comorbidities were also most likely to have received education.

Evaluating delivery models

Clearly, we needed to reach more people. We then tested various models for delivery. Historically, education had been provided in specialty diabetes clinics or hospital-based outpatient programs. Physicians gave patients a prescription to attend a class, and patients were expected to follow through. For a variety of reasons, that did not always work. To address this, we used the CCM with a focus on system redesign and
deployed a nurse educator to host diabetes clinic days in underserved federally qualified primary care clinics.

One story illustrates this nurse educator’s role. A patient, Jerry Smith, and his wife, Sandra, both had type 2 diabetes. With a limited income, they were paying $600 monthly for medications and supplies. Because Jerry’s condition was considered worse, Sandra stopped taking her medicine. Our nurse educator reviewed their circumstances, taught the Smiths how to improve their diet, and assisted them in obtaining supplies. As a result, they were able to keep their diabetes in control while dramatically reducing their expenses.

We repeated such services in a number of communities. Although we were unable to control for other variables, we did see a consistent improvement in glycemic control after education services were made available, and these improvements were extrapolated to a cost savings of > $500,000. We repeated this model in networks of not only rural, but also urban and suburban practices, also with positive results.

Next, we need to find out how to sustain the benefits of DSME. We know that self-management support needs to be ongoing, yet we have not determined the best methods in practice. We have collaborated with investigators from the University of Michigan and learned lessons from the Peers for Progress Program and trained our educators on empowerment-based approaches and peer support. In partnership with investigators at the Penn State Hershey Medical Center, we are implementing the PRISM (Program Reinforcement Impacts Self-Management) study.

Through this study, we are delivering DSME in three regions in Pennsylvania and comparing four different modes of self-management support follow-up after DSME is delivered by an educator.

Another area we are examining is how we can engage hospitalized patients in diabetes education. Thirty percent of our health system’s inpatient population has a diabetes-related diagnosis. We also know that 30% of Medicare patients are readmitted to the hospital after discharge. How can we stop this tide?

Currently, our diabetes inpatients learn survival skills from a staff nurse, usually as they are being wheeled to their car at discharge. Like many institutions, we no longer have an inpatient educator. We currently give all of our hospitalized patients with diabetes an outpatient education appointment at discharge and a self-management DVD designed to provide some basic survival skills, but more importantly, to reinforce the need for patients to participate in outpatient education.

**Examining population health**
The bottom line is, if all educators do not participate in reporting data, we will not be able to demonstrate our effectiveness, which leads to proper reimbursement and other improvements. So, our next area to explore is how best to manage population health with technology and how best to measure and report population outcomes.

Several years ago, we worked with the AADE in evaluating the AADE Outcome System online patient assessment tool. We found that patients even in poor communities found completing an online education assessment before their visit with an educator quite useful. Patients reported high satisfaction with the questionnaire, noting that it gave the educator good information and provided a good basis for discussion in education sessions. This system prepared them for their visit.

With 47 education programs, our UPMC educators were frustrated by the amount of time needed to review patients’ history during their visit, the paper documentation required, and the inability to aggregate and review their program data. We worked with our educators to design and test a data management system called Chronicle, which collects and generates reports on patients’ educational and clinical data, as well as behavioral goals and plans for achieving them. The system also tallies and reports aggregate information for the entire education program to help it tailor its services to the needs of its population. The system also inputs data directly onto an ADA recognition program application, eliminating piles of paperwork. We have shared our online system with the ADA education recognition program, which will offer it to educators nationwide.

**Fostering innovation**
Today’s fast-moving world demands innovation. For example, with the shortage of diabetes specialists, we need new ways to get services to our patients. Through PRIDE, we are using video-conferencing to connect an endocrinologist to patients and an educator at a rural site. We refer to this as our TREAT (Telemedicine for Reach, Education, and Treatment) study. The endocrinologist collaborates with the educator and patients to develop management plans. The endocrinologist trains and provides support for the local educator, who in turn provides ongoing medication management for patients.

There are several expected benefits for this approach: 1) the rural nurse gains experience with medication management, 2) patients receive the benefit of intensified management, and 3) local primary care providers have support for challenging patients.

Innovation does not necessarily have to be delivered through computers and mobile phones, however. A creative approach to reaching patients is through Diabetes Conversation Maps. I had the opportunity to work with ADA and some seasoned educators to develop the first American Diabetes Conversation Map. These group education tools are yet another way to move from giving traditional lectures to actively engaging patients in the educational process.

**Improving primary prevention**
Educators can also serve as a community-based resource for primary prevention. Some may say it is obvious that nurses and especially dietitians know nutrition and prevention approaches. However, I would argue that, although we are experts in treating patients who have diabetes, we are not always equipped...
to work with those at risk of developing diabetes.

Toward that end, my colleagues and I examined the role of educators as preventionists. We trained diabetes educators to deliver a modified Diabetes Prevention Program lifestyle intervention to people at risk for diabetes who were referred to their programs, with promising results.23

Our educators, along with many others, are also participating in the Group Lifestyle Balance training while we are working with colleagues from the CDC on a recognition program for prevention that you will be hearing more about in the near future.

Our diabetes prevention support team has trained > 600 participants, including U.S. military health care personnel, who are challenged with a burgeoning population of recruits and retirees at risk for diabetes.

Advocating for people with diabetes
Although all of these initiatives are important, the way to make things stick is through legislation and policy. In all of our studies, we collected data using the CCM as our framework.24–27 Then, Dr. Robert Gabbay from Penn State and I worked with our state health department and organized stakeholders to develop a Pennsylvania Diabetes Action Plan to set our course.18,28 As our former governor was presenting his Prescription for Pennsylvania initiative, these stakeholders encouraged him to take on diabetes in Pennsylvania. We had built the plan with evidence, and as a result, the CCM is being deployed across Pennsylvania.

The model is part of the Patient-Centered Medical Home initiative. Through it, our practitioners are asked to document not only traditional process measures, but also self-management goals. In all four regions of Pennsylvania, patient self-management goals are being established and documented in the medical homes.

Enlightening our health care decision-makers is crucial. This may include participating in advocacy initiatives with organizations such as ADA, meeting with Congressional representatives, advocating locally for people with diabetes, or sharing successes with the health ministries of other countries.

Thinking globally
Finally, diabetes is a worldwide disease that requires a global viewpoint. There is growing interest in diabetes education around the world. Educators are working on international standards and curriculums, world leaders are supporting education through health policy, and researchers are developing international studies. There are also many ongoing workshops and training programs to teach people in the trenches to evaluate and share their experiences at international meetings such as the International Diabetes Federation (IDF) World Congress in Montreal, where I had the opportunity to serve as the first woman and educator chair of an IDF Congress.

Translation research is being considered and funded on a global level as well. For example, the IDF’s Building Research in Diabetes Global Environments and Systems (BRIDGES) program supports translation studies around the world.

We need to continue to engage our government agencies to support these kinds of studies and to pique the interest of industry partners and foundations. We also need to consider getting involved in outreach efforts to secure donations of supplies and medications for countries in need.

Summary: The Road Ahead
As the diabetes epidemic continues, we all need to consider joining efforts in primary prevention. Furthermore, those who already have or will develop diabetes will require more health care and self-management support. We know that education and team care improve outcomes and that team members are able and willing to assume more responsibilities. Our current health care systems lack access, and reimbursement for needed services is limited.

We have reached a crossroads in our journey; we are gaining attention in this era of health reform, and we need to keep moving forward. To do so, we must better organize care and document and report its outcomes;

Figure 5. First patient Jerod, age 40.

demand patient-centered team care and seek ways to expand the roles of all disciplines involved in diabetes care; be innovative and explore new models of care delivery; participate in advocacy initiatives; and think in terms of both our local populations and global health.

In closing, you may be wondering whatever became of Jerod, my first patient with diabetes. Jerod is now 40 years old, married, with two children (Figure 5). He is a mountain-climber, and, believe it or not, he makes prostheses for a living. You can’t tell me that support and education has not helped him along his life journey.

I wish you well on your own road and hope that you go back to your respective communities and make education available to your patients. And if you get weary, remind yourself that self-management education works. Jerod and countless other of my former young patients who are now healthy adults are living proof of effective diabetes education.

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