As American Diabetes Association (ADA) President, Health Care & Education this past year, I have enjoyed a unique opportunity to interact with diabetes educators representing a variety of different practice settings from all across the United States, as well as from many different countries in other parts of the world. As my year unfolded, I began noticing some common issues and concerns that kept coming up. As a result, I have spent quite a bit of time reflecting on the role of diabetes self-management education (DSME) today in the treatment of diabetes and particularly on three key issues that I see challenging our ability to deliver quality DSME.

The prevalence of type 2 diabetes has virtually exploded over the past 20 years. The Centers for Disease Control and Prevention (CDC) estimates that the incidence of diabetes is 1.3 million new cases annually.1 Many of us have seen the CDC’s colored maps.2 These maps graphically illustrate the notion that our health care delivery system may be becoming overloaded from the challenge of treating > 18 million Americans with diabetes, to say nothing of the 41 million with prediabetes.3

Today, we have access to more and better pharmaceuticals and newer technologies than ever before to aid in the effective medical management of diabetes. So how well are our patients doing? Are Americans with diabetes winning or losing their war on diabetes?

**Measures of Clinical Success**

One well-regarded national measure of success is the National Committee on Quality Assurance (NCQA) Health Plan Employer Data and Information Set (HEDIS). This quality management tool is used by many health care professionals and policy makers to evaluate the quality of performance in key areas such as diabetes management. The NCQA 2004 State of Health Care Quality Report cites HEDIS data showing that 15% of diabetes patients covered by commercial insurance plans did not receive even one hemoglobin A1c (A1C) test within 12 months and that 32% of those who did have an A1C test were found to have values > 9.5%.3

In January 2004, the National Institute of Diabetes and Digestive and Kidney Diseases issued a press release cautioning America about a recent study showing that < 12% of people with diabetes were meeting the recommended goals for blood glucose, blood pressure, and cholesterol.4 And in May 2005, the American Association of Clinical Endocrinologists publicized the results of a recent survey of 157,000 adults with diabetes that found that 61% of those surveyed did not know what an A1C test was and that a high percentage were not achieving desirable A1C goals.5

It seems that even with an abundance of pharmaceutical choices and the availability of the latest self-management technology, far too many Americans with diabetes are not achieving the recommended clinical goals.

**DSME**

Since the 1980s, there has been a growing awareness of and appreciation for the need for quality diabetes patient education. But what do we mean when we talk about quality diabetes education? Who is qualified to provide and bill for this service? Which patients should receive diabetes education? How often should they receive follow-up?

To answer these questions and others, I believe it is first important to make sure we understand what we mean when we talk about quality diabetes education. For example, when Mary Frank, MD, a family physician and president of the American Academy of Family Physicians (AAFP), thinks about diabetes education for her patients, how do you suppose she would define the scope and process for delivery of quality diabetes education? How would she decide how and when to integrate a referral to a diabetes educator into a patient’s ongoing care? And when Dr. Frank puts on her AAFP president hat and collaborates with other family physicians on recommendations for professional practice guidelines for other primary care physicians, would she advocate for use of the ADA’s National Standards for DSME or perhaps apply other standards?

How about the medical director of a large insurance company, someone like William Popik, MD, who in March 2005 was named chief medical officer of Aetna, which administers health benefits for > 18.3 million members nationally. How would someone in Dr. Popik’s position decide which claims for diabetes education services to cover? And how many visits do you think would be
allowed over a lifetime of care for a person with diabetes?

Now think about someone in public office, for example, U.S. Representative Nancy Johnson, who is chair of the House Ways and Means Subcommittee on Health. When she is called on to consider health care expenditures, how does she look at the value of expenditures related to diabetes education? What would she say about DSME’s role in the escalating costs of diabetes and its complications? What would she define as quality diabetes education?

**National Standards for DSME**

The definition of quality diabetes education most frequently used by diabetes educators is that found in the National Standards for DSME. These are published each January in a supplement to the journal *Diabetes Care*. In these standards, we find the term DSME defined as “an interactive, collaborative, ongoing process involving the person with diabetes and the educator(s). This process includes 1) assessment of the individual’s specific educational needs; 2) identification of the individual’s specific diabetes self-management goals; 3) educational and behavioral intervention directed toward helping the individual achieve self-management goals; and 4) evaluation of the individual’s attainment of identified self-management goals.”

Many other definitions of diabetes education also exist, both within the United States and internationally. The International Diabetes Federation, for example, uses the term “therapeutic education,” defined as “education that results in the person being willing and able to self-manage their disease to the best of their ability using the health care professionals as a resource. Therapeutic education is an essential part of the clinical care of diabetes and includes consideration of the physical, psychological, cultural and spiritual aspects of diabetes care to ensure a holistic approach is adopted.”

For people with diabetes, other definitions include those provided by insurers regarding covered benefits for diabetes education. Those of us who work directly with provision of DSME to people with diabetes know that these definitions vary tremendously and create real barriers for people with diabetes in understanding and accessing quality DSME.

The ADA advocates for access to quality education for all people with diabetes. It not only endorses the National Standards for DSME, but also took action in 1986 to establish the Diabetes Education Recognition Program. This program assesses and certifies whether diabetes education programs seeking recognition are meeting the national standards.

This past year, the ADA and the American Association of Diabetes Educators (AADE) initiated a co-sponsored joint task force on DSME. This task force, cochaired by Carolé Mensing and Mary Austin, is working to identify a range of different models for DSME currently in use in the United States today. Additionally, the task force will examine the outcomes data currently available for measuring the success of these models. The report of this task force will help the boards of both organizations assess the appropriateness of the current standards for DSME and consider the best opportunities for research or other activities to further enhance quality DSME in the United States.

**Availability of Evidence-Based Guidelines**

The ADA annually publishes evidence-based clinical practice recommendations and standards of medical care for health care providers providing medical management of diabetes. These guidelines are highly regarded and accepted as the authoritative source for evidence-based clinical guidelines in the United States and also are frequently cited and referenced in other countries. One of the reasons for this acceptance is the scientific rigor applied to reviewing and updating the guidelines.

These guidelines provide a valuable road map for patients, health care practitioners, employers, health benefits managers, and a variety of other stakeholders, all seeking to continuously improve the delivery of cost-effective quality diabetes care. So what guidance do they provide on DSME? If we look closely at the guidelines, we find terms such as “DSME,” “therapeutic lifestyle change,” and “patient education and counseling” sprinkled throughout. Since the publication of the Diabetes Control and Complications Trial in 1993, there has been growing consensus that diabetes education is a core component of quality health care for all people with diabetes. This is emphasized in the opening sentence of the ADA position statement “Standards of Medical Care in Diabetes,” which reads “Diabetes is a chronic illness that requires continuing medical care and patient self-management education. . . .”

Although the guidelines clearly and repeatedly support the concept of diabetes education, they do not provide specific guidelines for when or how often DSME should be provided as a routine component of ongoing care, and they do not provide primary care providers, who see most Americans with diabetes, with any specific guidance or recommendations regarding when to refer patients to a structured DSME program that meets the national standards.

Of the recommendations published in the ADA Standards of Care document, eight contain specific references to DSME or medical nutrition therapy (MNT). Of these, five are scored as having been based on level E, or consensus-based evidence, and three are attributed to level A or B evidence, which is evidence based on peer-reviewed, randomized studies. Of the three attributed to level A or B evidence, two relate to MNT, and the third focuses on education related to self-care and the prevention of diabetes-related foot complications. The lack of more rigorous evidence has triggered calls for more research to better define the best methods for empowering patients to achieve better clinical outcomes.

**Evidence for the Effectiveness of DSME**

In 2001, Norris et al. published an extensive and much acclaimed meta-analysis of randomized trials on DSME in patients with type 2 diabetes. They reported on 72 studies described in 84 articles and concluded that there is evidence that DSME does support achievement of positive clinical outcomes in the short term. They went on to call for more research to better determine which DSME interventions are most effective to support sustained clinical outcomes.
The following year, Norris et al.12 published yet another article, this one reporting on their analysis of 31 published studies of the effect of DSME on A1C. Patients in the reviewed studies showed improved A1C results after DSME that were sustainable, at least in the short term, along with ongoing health care provider contact. But A1C levels rose once again within 1–3 months of cessation of contact with health care professionals. Again, the authors concluded that more research is needed to learn more about how to better support people with diabetes in attaining and sustaining longer-term glycemic control.

In 2003 Davidson13 published the results of a small randomized trial in which he compared the outcomes of 99 low-income minority patients receiving nurse-directed care to those of 80 matched patients receiving physician-directed care. He found that the patients whose care included nursing interventions experienced better short-term glycemic control than those seen only by a physician.

Additionally, there is impressive evidence from Trento and Porta,14 who practice in Italy. In 2001, they reported on a 2-year study of a cohort of 90 patients who began with a mean A1C of 7.4 ± 1.4%. A1C control was sustained more effectively in the 43 patients who were seen in an informal small group (mean A1C 7.5 ± 1.4%), than in the 47 others who were followed individually (8.3 ± 1.8). This study involved the health care team transforming a traditional patient exam room into an informal small-group educational program. The authors followed 84 of these patients continuously for 5 years and in 2004 reported again on their outcomes. The 42 patients who continued to be followed in the small-group setting had a mean A1C of 7.3 ± 1.0%, compared to a mean A1C of 9.0 ± 1.6% in the 42 who were seen one-on-one.15

To summarize, then, there are challenges related to the need for more A- and B-grade evidence on DSME. I am hopeful that the completion of the work of the AADE/ADA task force on DSME will help us actively pursue more peer-reviewed, randomized trials to help us answer important questions such as:

- Do all DSME programs that meet the national standards yield sustainable clinical outcomes? If not, which models of DSME are most effective in helping people with diabetes improve and sustain outcomes for glucose, blood pressure, and cholesterol?
- Is it possible that DSME as defined in the national standards is only a subset of quality diabetes education programs? And is it possible that perhaps different levels of programs, and of diabetes educator skill sets, might be applied to risk-stratified populations to yield better outcomes for less cost?

**Limited Assess to DSME**

Access to quality DSME is an important issue for individual patients and for our nation’s public health system as we face the crisis of escalating numbers of Americans with diabetes, pre-diabetes, and obesity. One key access issue is the grossly insufficient number of qualified and credentialed diabetes educators and ADA-recognized education programs to address the care of the nearly 60 million individuals with pre-diabetes or diabetes in the United States. Today, there are mandates in 46 states for insurance coverage for diabetes education, and, as of May 2005, there were 1,914 ADA-recognized education programs in 2,791 sites, with ~150 more under review.

ADA recently announced plans to implement new procedures allowing managers of recognized programs to deliver their programs more flexibly, in more locations in the communities they serve, closer to where people with diabetes live and work. With luck, this could make quality diabetes education more accessible for more people with diabetes.

**Availability of Diabetes Educators**

How many credentialed diabetes educators are available to provide DSME? Let’s start to answer this by looking at the number of certified diabetes educators (CDEs) reported by the National Board of Certified Diabetes Educators (NBCDE). As of May 2005, NBCDE’s database showed 13,987 CDEs, of whom 56% were nurses, 37% were dietitians, and the remainder were from other disciplines (e.g., pharmacists, physicians, physician assistants, exercise physiologists, and behavioral medicine specialists).

It is important to keep in mind that not all CDEs are actively involved in clinical positions through which they provide DSME. Some are primarily working in academic, administrative, or medical sales positions, and, sadly, too many have lost or may be at risk of losing positions as hospitals and health maintenance organizations have closed diabetes education programs or are reducing the number of full-time positions dedicated to diabetes education.

Another key indicator of the number of available diabetes educators is the membership of AADE. As of May 2005, AADE had 10,434 members, of whom 52% were nurses, 28% were dietitians, and the remainder were from other health care disciplines.

As of April 2005, ADA’s category II professional membership included 4,732 members that were predominately diabetes educators (63% were nurses, 27% were dietitians, and the remainder were from other health care professions).

Among these three organizations, we find information that provides interesting information on subsets of diabetes educators, many of whom are counted by all three organizations. Clearly, it appears that there is a disproportionate relationship between the number of people with diabetes and the number of credentialed diabetes educators available to provide their DSME.

**ADA’s Support of DSME**

So what is the ADA doing about this? Quality DSME is mission-centric to the association. Accordingly, the ADA will continue to advocate for patient access to quality diabetes education. To support educators interested in applying for ADA recognition, the ADA’s online bookstore provides everything needed for a successful application.

ADA is also committed to ongoing enhancement of online information (available at www.diabetes.org) for people with diabetes and their health care providers. The ADA website is offering more interactive learning resources to help people with diabetes.
be more successful with positive lifestyle management. Some examples of ADA empowerment tools (online or in print) include:

- “Ask the Pharmacist,” through which patients can submit online questions about any medication and receive a personal email response from a pharmacist within 1 business day.
- A virtual grocery store, where users can take a tour to learn how to be more savvy shoppers or select recipes from ADA cookbooks and print grocery shopping lists for ingredients.
- “ClubPed,” an innovative behavior modification program that focuses on helping people become more physically active.
- “Diabetes PHD,” which stands for Personal Health Decisions and offers people the opportunity to forecast their personal health risks for diabetes, heart attack, stroke, kidney failure, eye problems, and foot problems. Users can then see how changes in their weight, blood glucose, blood pressure, cholesterol, or other factors may change their risks. If they begin considering the possibility of achieving such changes, the site includes links to “how-to” information.
- “Visit Planner,” a tool providers and patients can use collaboratively to help get the maximum benefit out of each contact. These can be obtained through the ADA call center (1-800-DIABETES).

ADA will be adding more tools in the coming months, all designed to support people with diabetes and their health care team in achieving and sustaining better clinical outcomes.

Conclusions
I would like to close with some wise words from ADA Past President Alan Cherrington, PhD, my fellow principal officer and a champion for quality diabetes education. Dr. Cherrington’s parting words to the ADA leadership team at the end of his term as president were to remember three key things: “What matters is success, it’s all about innovation, and always remember that what we do is all about people with diabetes.”

Dr. Cherrington’s words offer direction for diabetes educators, as we consider the possibilities for the future of DSME:

What matters is success, and our success is linked with that of empowering our patients to achieve their goals for quality health care. It is all about innovation, and I think it may be time for diabetes educators and their professional organizations to critically reassess the national standards for DSME to see if they continue to adequately address the needs of people with diabetes. Additionally, let’s consider innovative virtual research. The opportunity exists today to use mathematical modeling technology, such as Archimedes, the system developed by Kaiser Permanente and now used to operate ADA’s PHD program, to conduct cost-effective virtual clinical trials. This could reduce the time needed to collect better evidence supporting recognition of the most effective DSME models and perhaps lead to clearer DSME recommendations in the ADA’s clinical practice guidelines. And yes, it is all about people with diabetes. No group knows better than diabetes educators how vital it is to focus on the people directly affected by diabetes, their issues and concerns, and how we can best be of help and support to them in their journeys.

References

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