

Waging Battle Against the Epidemic

Improving Diabetes Care in North Carolina

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NORTH CAROLINA AND THE NATION are facing an epidemic in type 2 diabetes and its related risk factor, obesity. Between 1990 and 1998, diabetes increased 33% nationwide;¹ in North Carolina it increased 42% between 1995 and 1999.² At the same time we face this terrifying increase in diabetes prevalence, we have exciting new evidence that diabetes can be prevented. A large US-based trial and several foreign trials suggest that, in high-risk individuals, exercise and weight loss can lower diabetes risk by almost one half.³

Because of this new evidence, most public attention to the epidemic of diabetes has been focused on *prevention*, and on the exercise and dietary habits of our population that have led to a rise in obesity, a key risk factor for type 2 diabetes. These are important concerns, which deserve renewed public health and policy initiatives as well as the attention of healthcare professionals.

We cannot, however, shift our attention and resources away from the pressing problem of assuring *effective treatment and self-management* of those persons already diagnosed with diabetes. Diabetes is the fifth leading cause of death among North Carolinians, and hospitalizations with diabetes as the primary cause accounted for \$117 million health care dollars in 2000.² Diabetes is a leading cause of blindness, renal failure, and amputations. North Carolina, ranked 16th in the nation in diabetes prevalence,⁴ faces an economic burden that will only grow with the increasing numbers of persons diagnosed with the disease. In addition, health disparities by race or ethnicity are substantial: prevalence among African Americans is 9.0%, as compared to 5.9% in whites, and age-adjusted mortality is 2.5 times greater among African Americans than whites.²

There is growing evidence that, with effective treatment of patients with diabetes, the complications and the economic costs associated with the current burden of diabetes

are also preventable.⁵⁻⁹ Medical care for patients with diabetes, however, has been demonstrated in multiple studies and among all types of providers to be inadequate. Fortunately, care for diabetes patients can be improved. In the last decade, advances in treatment—and more importantly, in the design of clinical care systems for patients with diabetes and other chronic diseases—offer exciting and effective solutions to the familiar problems of changing provider and patient behavior. In this article we review this evidence and focus on two areas of concern, quality of medical care and access to self-management education, and we highlight state and local efforts to address gaps in these areas. North Carolina faces an urgent need for more directed and cooperative efforts, as well as more resources to fund these efforts, to improve medical care and self-management of this disease.

Quality of Care: Clinical Standards as the Starting Point

Standards of care for patients with diabetes focus on laboratory tests, elements of the physical exam, use of appropriate medications, and counseling by the provider. Standards published by the American Diabetes Association (ADA), which are updated yearly, are the most-often used reference for quality of care measures for patients with diabetes.¹⁰ In North Carolina, *Patterns of Care: Guidelines for Diabetes Care in North Carolina (POC)*, developed by the NC Diabetes Advisory Council and adopted by major provider organizations, is based on the ADA recommendations. Two other sets of measures often referenced are HEDIS (Health Plan Employer Data and Information Set, developed by the National Committee on Quality Assurance, or NCQA) and DQIP (Diabetes Quality Improvement Program, developed by

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Centers for Medicare and Medicaid Services, ADA, NCQA, and other partners).¹¹ Although some of these documents are developed specifically as guidelines for patient care and others for quality assurance and accountability for providers, all are used to develop quality of care measures. While small discrepancies exist among the different guidelines (for example, in the level of blood pressure control), they are generally in agreement, and increasingly the available guidelines describe the evidence (i.e., clinical trials or observational studies) on which the recommendations are based.

Together these documents lay out standards of care for patients with diabetes, which include

- ◆ monitoring and treating hyperglycemia
- ◆ monitoring for and treating elevated blood pressure and elevated cholesterol
- ◆ monitoring for evidence of kidney or eye damage and referral for treatment
- ◆ routine examination of the feet
- ◆ recommending appropriate immunizations.

Nationwide and in this state, we know we fall far short of our treatment goals in these areas. A national report card published by the Division of Diabetes Translation of the Centers for Disease Control and Prevention (CDC) used data from two national surveys to document DQIP measures, and it found that substantial numbers of persons were not receiving needed procedures.¹² For example, only 29% had the recommended number of HbA1c tests (which measure blood sugar levels over time), and only 18% had HbA1c levels higher than a critical cutoff. Although 85% of persons had the recommended test for cholesterol levels, only 42% had acceptable cholesterol control. Only 66% had acceptable blood pressure control, 63% had the recommended eye exam, and 55% had the recommended foot exam.

Data from North Carolina indicate the same gap between desired and actual care. Using data from a telephone survey and comparing to *Healthy People 2010* goals, a recent analysis of trends in these measures for North Carolina persons with diabetes had very sobering results. For only two of six measures (glycosylated hemoglobin testing and self monitoring of blood glucose) will we reach the published goals by 2010 (see the article by Donahue, et al, on page XX). Several other measures appear to be on the increase but will not reach 2010 goals (immunizations); and the rate of foot exams is actually decreasing. Other analyses by the NC Diabetes Prevention and Control Program (DPCP) provide estimates of the number of persons at risk for complications because of care not delivered. Seventy-four thousand persons are at risk because they have not received a recent foot exam; 118,300 have not had the recommended eye exams; and 208,300 report no prior diabetes education.²

Using the Chronic Care Model to Improve Quality

How is the busy clinician or the financially challenged office practice to improve these numbers? How is the man-

aged care system or the hospital quality improvement office to address these issues system-wide? Although numerous interventions have been attempted, a major step forward in our understanding of how to advance care for diabetes patients came with the publication of the Chronic Care Model (CCM).¹³⁻¹⁵ The model was developed by Dr. Edward Wagner, former professor of medicine and epidemiology at UNC-Chapel Hill and currently Director of the W. A. Sandy MacColl Institute for Healthcare Innovation at the Center for Health Studies, Group Health Cooperative of Puget Sound. The CCM presents a multidimensional view of the patient-provider interaction, and identifies six separate components of care to target for improvement. The overall goal is to create an informed, activated patient who interacts with a prepared and proactive clinical team to produce better outcomes. The six principal components of this model are

- ◆ clinical information systems
- ◆ decision support
- ◆ delivery system design
- ◆ self-management support
- ◆ healthcare organization
- ◆ community resources

In each of these components significant modification of the behavior of the healthcare provider/system is possible, and thus the model represents not only a "vision" of effective chronic illness care but also a template against which the care processes can be assessed in an ongoing manner. Through the use of the model, health care providers and managers can maintain sharp focus on key process and outcome indicators in order to achieve overall improvement in patients' health. Of note, a manual developed for quality improvement initiatives based on the CCM is publicly available and describes concrete steps to achieving change.¹⁶

Although the Chronic Care Model is a relatively recent development, carefully executed research is already available to support its effectiveness. Systematic reviews and meta-analyses support the premise that improving elements of the Chronic Care Model, such as information systems to facilitate the regular review of the medical care provided to patients,^{14, 17} self-management education,^{14, 18, 19} and decision support and delivery system design,¹⁴ can improve care for patients with diabetes. Finally, recent recommendations from the Task Force on Community Preventive Services, an independent, nonfederal body whose work is supported by the Centers for Disease Control and Prevention, complement this body of research. The Task Force strongly recommends two health care system interventions, disease management and case management, to improve care for patients with diabetes.^{20, 21}

Improving Care for Patients with Diabetes in North Carolina

The Chronic Care Model, and the research and Task Force recommendations that support it, supply medical and public health professionals with powerful, evidence-based strat-

Table. North Carolina initiatives to improve quality of care for patients with diabetes

<i>Project/Years</i>	<i>Description/Partners</i>	<i>Target</i>
Patterns of Care 1996	ADA-based guidelines developed by the NC Diabetes Advisory Council	Healthcare organizations Clinicians
Asheville Project 1997-present	Pharmacist-based diabetes education and case management; partnership among city of Asheville, local hospital, a diabetes education center, and community pharmacists	Employees of city and hospital with diabetes
Managed Care Diabetes Project 1998-2002	Chart review study and intervention, including direct mailings to patients; Medical Review of North Carolina; Division of Medical Assistance, NC DHHS	Managed care Medicaid patients
Project IDEAL (Improving Diabetes Education, Access to Care, and Living) ^{26,27} 1999-2002	Initiative to improve quality of life and quality of care for underserved patients with diabetes, funded by the Kate B. Reynolds Charitable Trust and managed by Wake Forest University	14 organizations serving the underserved
Health Disparities Collaboratives 1999-present	Nationwide effort sponsored by the Bureau of Primary Healthcare, also modeled on the CCM and IHI Collaboratives; Participating community health centers; NC Primary Healthcare Association	Patients in community/ migrant health centers
Model for Collaboratively Managing the Public's Health 2000-present	Investigation of best practices in diabetes care; UNC School of Public Health; Medical Directors Committee of the NC Association of Health Plans	
Diabetes initiative within ACCESS II/III 2000-present	Quality improvement initiative based on the Chronic Care Model and strategies developed by the Institute for Healthcare Improvement (IHI) ²²	Managed care Medicaid patients
Project REACH 2010 2001-present	Federal initiative to address health disparities; two sites in NC addressing diabetes prevention and control	Two target communities in NC
North Carolina Diabetes Collaborative 2003	Statewide quality improvement collaborative sponsored by the DPCP and partners	15 primary care practices

egies for improving care for patients with diabetes. To what extent have these strategies been adopted in North Carolina?

Quality improvement can take place in one office, with one provider, or can happen at a system level. Although many individual providers have implemented efforts to im-

prove the care of their patients—for example, by using a flowsheet to document preventive care delivered—it is change at the system level that has the greatest potential to improve the care for diabetes patients as a whole. Several large-scale projects to improve care for patients with diabetes are under way in North Carolina (see Table), but only three are based

on the Chronic Care Model. All three projects also utilize a collaborative quality improvement process developed by the Institute for Healthcare Improvement,²² whereby practices meet regularly over the course of a year and implement changes in their practices using improvement techniques developed for industry.²³ Two of these collaboratives were developed for specific populations (providers participating in Medicaid managed care and community health centers), and a final collaborative conducted by the NC DPCP has enrolled a variety of practice types. Data are not yet available from any of these North Carolina activities, but evaluation of national collaboratives suggests notable improvement in elements of diabetes care such as measurement of HbA1c.²⁴ For example, the Bureau of Primary Healthcare reports a 300% increase in the number of patients receiving the appropriate number of HbA1c tests in the course of the one-year collaborative.²⁵

These projects have the potential to reach large numbers of participants, but at the current level of activity and funding, they probably cannot have an impact measurable at the population level. Only eight of 21 potential community health centers have participated in the Bureau of Primary Health Care (BPHC) Health Disparities Diabetes Collaboratives. Only 14 practices are enrolled in the collaborative sponsored by the NC DPCP, which itself has only one year of funding from the Robert Wood Johnson Foundation for this activity. Given the promise of these initiatives at the national level, new sponsorship and support are needed for state-based activities. Documentation of early success will also be critical to sustaining these programs.

We await data from other quality improvement strategies under way in NC, including Project IDEAL (Improving Diabetes Education, Access to Care and Living), an initiative funded by the Kate B. Reynolds Charitable Trust and managed by Wake Forest University, to improve quality of care and quality of life for underserved patients with diabetes.²⁶ IDEAL sites had low levels of quality of care in the program communities at baseline²⁷ and showed significant improvements in most care indicators measured after the implementation of the site-specific interventions (R. Bell, personal communication).

Lessons learned across projects are already apparent. Resources are an issue at a system level and at the level of individual practices. The evidence for the economic benefits of improving diabetes care is suggestive, but not definitive,^{9,14} and how the evidence is interpreted depends on one's perspective, whether provider, health system, public health agency, or the general society. In addition, sustainability of these efforts has yet to be documented. Also, most of our current efforts to improve diabetes care are limited in that they are developed for one system of care only. Collaborative efforts across systems of care are difficult, hard to fund, and may be perceived as less effective. Still, combining resources of different payor sources and agencies may be the best strategy to develop quality improvement programs that have wide reach and that are sustainable.

The Activated Patient and the Role of Self-Management Education

A key component of the Chronic Care Model is the active involvement of the patient in his or her own care. Because of the need for daily self-care (for example, self-monitoring of blood glucose, diet and exercise, and foot self-exam), and the limited amount of time spent face to face with their doctors, patients with diabetes essentially become the most important providers of care. The adult patient with diabetes will ideally understand basic facts about the disease and its treatment, will be comfortably conversant with healthcare professionals about management of his or her disease, and will be actively engaged in the requisite list of self-care behaviors.

Patients can learn these self-management skills on their own, but this is somewhat unusual. Instead, trained instructors, usually Certified Diabetes Educators (CDEs), nurses, or nutritionists, deliver the essential information and guide the patients in practicing the skills to help patients achieve a high level of effectiveness and feelings of self-efficacy in their self-care. While primary healthcare providers may not actually provide this information and skill training themselves, they need to know how to access these services for their patients.

Access to Self-Management Education: Multiple Barriers

Despite strong evidence for the effectiveness of self-management education,^{18,19} only one half of patients with diabetes in North Carolina report ever having had a diabetes education class.² National data suggest that certain patients, such as the uninsured, are less likely to have received self-management education.²⁸

Geographic barriers to accessing self-management education are significant in North Carolina. Diabetes education takes place in a variety of sites (health departments; clinics or physician offices; specialized diabetes care and education centers). The largest and arguably the best of these sites are recognized by the ADA as achieving national standards in self-management education. Similarly, diabetes education is conducted by persons with varied types of training (CDEs, RNs, nutritionists, pharmacists). Although the quantity and distribution of the supply of care is thus difficult to determine, we know that in North Carolina there are

- ◆ 79 ADA-recognized sites for diabetes education, covering only 51 of 100 counties²⁹
- ◆ 128 Certified Diabetes Educators (based on membership data from the American Association of Diabetes Educators), covering 47 of 100 counties³⁰
- ◆ four community college partnerships offering diabetes education classes.

Although other sources of diabetes education cannot be quantified (including dietitians and nurses in health depart-

ments, managed care plans, and private practices), clearly diabetes education is not accessible in all of North Carolina.

One initiative developed in 1987 to address this need is the Clinical Fellowship on Diabetes at East Carolina University's Brody School of Medicine. This intensive five-day training course for nurses, dietitians, pharmacists, and other providers has been supported since 1989 by the Diabetes Prevention and Control Program. Since its inception, over 400 persons representing 80 counties have completed the fellowship. Importantly, a survey of participants in 1997 showed that over 40% either achieved the CDE credential or were working towards it.³¹

In addition to geographic barriers to education there are financial and personal barriers. We have no estimates of the number of diabetes education sites that accept uninsured persons on a sliding scale. Reimbursement for educational services is covered variably in different plans. Medicare will cover a limited number of hours of diabetes self-management training (DSMT) when training is furnished by a provider who meets certain quality standards, most often documented through ADA recognition. Medicaid provides similar benefits for DSMT. The passage of NC House Bill 5 in 1997 requires insurance and managed care plans that are subject to regulation by the North Carolina Department of Insurance to provide coverage for DSMT. Although these laws are positive steps towards appropriate coverage of benefits, the amount of coverage is suboptimal, and the reimbursement mechanisms are burdensome. The complexities of the regulations themselves represent a significant barrier not only to patients but also to providers of self-management education.

Coverage of testing supplies, crucial for self-monitoring and glycemic control,³²⁻³⁵ is as varied as coverage of the diabetes self-management education itself. Currently, both Medicare and Medicaid reimburse for a limited number of blood glucose meters, test strips, and lancets. Importantly, NC House Bill 97-5 also guarantees coverage for diabetes testing supplies by regulated health plans. Uninsured patients, however, may have access to supplies only through samples and special promotional offers. Since affordability of testing supplies is cited as the main barrier to home testing by patients and providers,³⁶⁻³⁸ uniform coverage by public and private health plans, as well as programs to provide supplies to the uninsured, is critical to improving patient self-management.

Beyond the geographic and financial barriers to self-management education are language and cultural barriers, which exist for many residents of North Carolina. Education that is offered in community sites, such as churches, schools, or recreation centers, may be more acceptable to some patients and thus more effective. A model for community-based diabetes education exists in North Carolina. Project DIRECT, funded by the Centers for Disease Control and Prevention (CDC), is a community-based diabetes prevention and control project targeted to African-American residents of Southeast Raleigh.³⁹ For patients with diabetes in this popula-

tion, self-management education takes place in community sites, such as recreation and senior centers, as well as in a local clinic. The curriculum for the classes was adapted from that developed by the NC Diabetes Advisory Council, with specific changes, such as in the nutrition session, for the target population. The self-management classes have enrolled 545 participants to date, approximately one third of whom were uninsured. Preliminary evaluation of data demonstrates improved knowledge and behavior as well as a trend towards improved glycemic control (A. Reese, NC DPCP, unpublished data).

Other models of self-management education tailored to underserved populations have been developed in North Carolina through Project IDEAL. Successful strategies included mobile units and satellite education centers as well as provision of education in community settings. Several IDEAL sites attained ADA recognition during the course of the initiative. The city of Asheville has also attempted to increase access to diabetes educators through an initiative that compensates pharmacists to provide diabetes education. Another mechanism with potential to increase access to self-management education is the Diabetes Today Program funded by the NC DPCP. Utilizing a CDC model of community coalition building and local assessment of patient needs, local health departments are funded by the DPCP to improve the identification and care for patients with diabetes community-wide. Several health departments in the last few years, notably those in New Hanover, Onslow, and Edgecombe counties, have used these funds to develop or increase their education services. However, the small amount of funding (typically 10 health departments per year at \$10,000 each for a maximum of 3 years) limits the reach of this initiative.

Lessons learned from these projects highlight potential solutions for increasing access to high quality self-management education. The NC DPCP has already committed to sponsoring the East Carolina University Fellowship and to promoting successful models of community-based education. However, to fully implement effective programs, additional federal and state support is needed. In addition, clinical and public health providers at the local level must come together to assess local availability of self-management education, and develop strategies to increase access. All providers of primary care need available, affordable self-management education for their patients, and it may be that only these providers can create the "demand" necessary to bring about change.

Emerging Issues

Recent evidence from clinical trials of patients with "pre-diabetes" (impaired glucose tolerance) demonstrates that diabetes can be prevented with weight loss and exercise.³ Although the public health and medical communities are eager to begin implementing diabetes prevention programs,

careful attention must be given to the limits of the evidence we have to date.

An effective prevention program must be based upon effective screening for pre-diabetes. Currently, we have recommendations for screening that are based on expert opinion, with no evidence from clinical trials. The ADA recommends screening for pre-diabetes in persons who are over age 45 and overweight (BMI \geq 25 kg/m²); it also recommends a consideration of screening for those under age 45 who are overweight and have at least one other risk factor for diabetes.⁴⁰ Importantly, the ADA recommends only opportunistic screening, i.e., screening that takes place in a clinical setting during a routine visit; it does not recommend community-based or mass screening efforts,⁴⁰ programs that often recruit healthier persons at a lower risk.⁴¹

An additional requirement for a successful diabetes prevention program is that effective treatment for pre-diabetes must be available. The intervention in the Diabetes Prevention and Control Program consisted of intensive individual and group education,³ which is not likely to be available for most persons and especially not for the uninsured. Thus, although clinical trials have demonstrated that, in very controlled settings, diabetes can be prevented, there is not sufficient evidence to implement wide-scale screening and intervention programs. Priority should be placed on supporting demonstration programs in clinical and perhaps community settings that can be properly evaluated. In the meantime, funds for community-based diabetes control are better spent in improving treatment and education for existing patients with diabetes.

A Call for Collaboration

Successful clinical management of the patient with diabetes depends on an effective collaboration between the patient and the provider. This principle holds true for the larger issues of improving care for all North Carolina patients with

diabetes and improving access to self-management education. Individual clinical providers as well as health care systems need to partner with public health agencies to get the job done.

Healthcare professionals provide the direct clinical services to patients, but they need accessible self-management education and other health promotion programs for their patients. The messages received in the provider's office on healthy behaviors must be reinforced by a healthy community environment, which public health agencies work to achieve. Health plans, professional associations, and individual providers need to recognize the importance of the environment and of community resources in the overall management of their patients. They need to reach outside their traditional roles and reach toward partnerships with other agencies.

While public health agencies lack the resources and the mandate to provide direct clinical services, they play a critical role in educating patients, in leading quality improvement, in developing and disseminating effective models of self-management education, and in developing appropriate policy. These agencies, including the DPCP and its advisory body, the Diabetes Advisory Council, as well as local health departments and other organizations, must develop the programs and leverage the resources in partnership with healthcare professionals.

Only a handful of projects in North Carolina effectively combine the tools of public health with the active participation, experience, and the local knowledge of healthcare practitioners. There is an urgent need for new local initiatives that connect the resources, knowledge and skills of all partners to confront the epidemic of diabetes in our state. There is an overarching need for more federal and state resources to disseminate and implement those projects that have been successful at the local level. As a state with one of the highest prevalences of diabetes, we are required to tackle these issues head-on. The epidemic calls us—now is the time to act.

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