Vision problems increase when disease is left untreated

As the number of diabetes cases increases, the number of people experiencing complications, including blindness, will also increase. For states, more blind residents means there will be an increase in people needing both medical and rehabilitative services.

By Jennifer Ginn
While legislators worry about health issues such as Medicaid costs, rising health care costs and the uninsured, one more concern is beginning to surface. The issue is the vision impairment and blindness that can result when individuals with diabetes do not adequately control their blood sugar levels. Diabetes is the leading cause of new cases of blindness among adults 20- to 74-years-old. With more Americans being diagnosed with diabetes at an earlier age, it is an issue that will become much larger as the population ages.

The Centers for Disease Control and Prevention estimates that in 2005, about 21 million people in the United States had diabetes, almost a third of whom were undiagnosed. Most of those cases were type 2, which occurs when the body becomes desensitized to the insulin it produces. Type 2 diabetes typically affects older adults and appears to be influenced by poor diet, obesity and a lack of exercise. Type 1 diabetes, which usually is diagnosed in children and accounts for 5–10 percent of all cases of diabetes, happens when the body’s immune system attacks the part of the pancreas that produces insulin.

“We with type 1 diabetes, we don’t have to worry too much about finding these individuals,” said Dr. Michael Duenas, health scientist and project officer with the Division of Diabetes Translation’s National Vision Program at the Centers for Disease Control and Prevention. “They’re going to get sick quickly with classic signs and symptoms and then they’re going to get diagnosed with diabetes. … With type 2 diabetes, we don’t know when the disease actually started as there may be few if any symptoms. Most people have type 2 diabetes nine to 12 years before they’re actually diagnosed. The problem is that complications can occur during the time they go undiagnosed.”

Why should legislators be concerned?

While uncontrolled diabetes can cause complications such as kidney failure, nerve damage and amputations, it also can lead to vision-threatening eye diseases. Diabetic retinopathy occurs when elevated blood sugar levels damage the blood vessels of the retina, causing them to break down, leak or become blocked. It causes 12,000–24,000 new cases of blindness each year. Individuals with diabetes also are more likely to develop cataracts and glaucoma, both of which can cause vision loss.

Diabetic retinopathy is not uncommon in the United States. A study published in the April 2004 issue of the Archives of Ophthalmology estimated that 4.1 million people aged 40 and older in the U.S. have diabetic retinopathy, which amounts to one of every 29 people. One in 132 people have vision-threatening diabetic retinopathy.

David Hoffman, chair of the Policy Committee of the National Association of Chronic Disease Directors, said the complications of long-term diabetes have not received the national or state policy attention and resources they need. “I don’t think diabetes is on the radar of many people generally, unfortunately,” he said. “It’s not something that’s going to attack us. It’s not something that is infectious that we need to be concerned about the communicability of the disease between people. … (Because) it’s a chronic condition that tends to develop very slowly and the complications then tend to develop very slowly, there’s not immediacy in the concern.”

As the number of diabetics grows in the United States, up 14 percent during the past two years, the number of people experiencing complications also will increase. For states, more blind residents means there will be an increase in people needing both medical and rehabilitative services.

“The complications are time related,” Duenas said. “Let’s say adults are developing diabetic retinopathy in their 40s and 50s. But if an individual develops diabetes at a younger age, he/she is going to start developing it in their 30s. We’re going to have significant retinopathy complications.”

Duenas said the total costs in the U.S. for all vision impairments—which includes such things as diabetic retinopathy, age-related macular degeneration, glaucoma and cataracts—is estimated at $68 billion annually. The financial effect of diabetes is already being felt in New York.

“To states, the implications are almost overwhelming,” Hoffman said. A report to the New York State Diabetes Task Force stated that “… in 2004, New York Medicaid paid $5.5 billion for the health care of people with diabetes. That’s a big number. When you look at the fact for children born today, it’s conceivable one in three will develop diabetes in their lifetime. For Hispanic females, it’s one in two. For African-Americans and Hispanics in general, it’s two of five.”

What are states doing?

The solution for diabetic retinopathy involves a two-pronged attack. The first part is to prevent diabetes. Research studies have found that moderate weight loss and exercise can prevent or delay type 2 diabetes among adults at high risk of diabetes. But once people are diagnosed, good control of blood sugar levels can prevent complications. Regular dilated eye exams are also a necessary component of preventive care for individuals with diabetes to detect problems when they are small and can be treated.

The Guide to Community Preventative Services, developed by a task force that provides leadership in evaluating strategies
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—Dr. Michael Duenas, CDC

To address a variety of public health topics, recommends three proven strategies to prevent and manage diabetes. The guide recommends:

- Identifying all those diagnosed with diabetes in the health care system, implementing care guidelines/performance standards and tracking, measuring and managing health outcomes;
- Assigning a case manager to plan and coordinate care for individuals with diabetes;
- Holding classes in community gathering places and homes to help diabetics learn how to manage their disease.

Education, said Duenas, is essential for legislators, medical professionals and the public.

“The problem is that what we see happening is some people, especially those among certain ethnic groups with a higher prevalence of diabetes, tend to feel that with such a high prevalence in my group, I’m eventually going to get diabetes,” Duenas said. “… With complication rates, (it’s) the same thing. This is often characterized by thinking that there’s nothing that can be done, therefore education becomes important.

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State efforts to combat diabetes and diabetic retinopathy also are centering on education.

Dr. Appathurai Balamurugan, senior epidemiologist for the Arkansas Department of Health and Human Services and assistant professor at the University of Arkansas for Medical Sciences, said a $10,000 grant from Prevent Blindness America is funding a year-long focus on diabetic retinopathy by the Arkansas State Vision Preservation Work Group. A series of workshops for primary care physicians will focus on the importance of yearly eye exams for individuals with diabetes.

In 2003, legislators and representatives from social service agencies and the medical field formed Ohio’s Aging Eye Public Private Partnership. The group, comprised of representatives from 20 public and private agencies and three legislators, is designed to raise awareness of the growing threat to the vision of residents in the state. Recent efforts have included launching a Web site (available at www.preventblindness.org/research/) that posts vision research and fact sheets on vision loss, a resource directory of eye care and vision rehabilitation services in Ohio and information on a symposium that brought together leaders from vision research, public health, aging organizations and legislators.

In New York, the Community Coalitions for Diabetes Prevention is a cohort of 15 regionally based partnerships that address preventing diabetes and its complications. There are diabetes self-management classes, community awareness events for at-risk populations and efforts to increase physical activity for children. For those who are already diagnosed with diabetes, there are campaigns to increase the number of patients getting foot exams, eye exams and flu and pneumonia vaccines, as well as an effort to increase the use of the hemoglobin A1C test. This tests gauges how well blood sugar is controlled during the past three months and should be used in conjunction with
home blood glucose meters, which measure an individual’s blood sugar at particular point in time.

Education is stressed in a San Antonio program funded by the CDC called Families Preventing Diabetes. Lucy Romero, senior public health nurse, said the program provides free diabetes education for patients and their families using trained volunteers—or promotores—in the highly Hispanic neighborhood. A series of 12 two-hour classes focuses on nutrition and physical activity. Romero said they also are working on how to provide free eye care to diabetics without insurance.

“What I’ve tried to do is link up with a few ophthalmologists here locally,” she said. “They were trying to pull together a free diabetes eye screening day. There are even plans to open up some slots and I can start sending folks over there with no insurance. … Some of these folks haven’t seen a doctor in years since they’ve been diagnosed.”

Sherill Williams, president and CEO of Prevent Blindness Ohio, said one stumbling block for vision programs is the same one faced by other sectors of health care. We live in a society that pays to treat sick people, not for programs that can prevent the illness.

“I think health care is a challenge for … every individual, every company, every state and every government,” Williams said. “It will continue to be a challenge until we come up with a formula for how to pay for health vs. illness. This is paying for health. … We pay for illness, we don’t pay for health.”

Balamurugan said it’s not too late for states to start looking at the looming threat posed by diabetic retinopathy among an aging population of individuals with diabetes.

“We kind of started late, but I think we were not too delayed,” he said. “This is an important priority, with the aging population and the epidemic proportion of diabetics. We know at some point, almost all the people with diabetes will develop retinopathy in their lifetime. It is closely related to the length of the disease.

“… The diabetes community has long known this is a priority. I think with individual states, we are trying to increase awareness about diabetic retinopathy and its potential burden in upcoming years.”

—Jennifer Ginn is a health policy analyst at The Council of State Governments.

What state policymakers can do …

Here are the recommendations made by professionals in the diabetes, chronic disease and eye disease fields about what legislators can do to help their states prevent more diabetics from developing vision-threatening complications.

- Talk to your state’s Behavioral Risk Factor Surveillance System (BRFSS) coordinator to find out what your state is doing to monitor eye disease and access to eye care. BRFSS, a yearly telephone survey of health behaviors developed by the CDC, began offering a vision module in 2005. “Gaining state-specific data on vision is really an important thing to consider,” said Dr. Michael Duenas, health scientist and project officer with the Division of Diabetes Translation’s National Vision Program at the CDC. “It allows state legislators to look at their state in relationship to other states and allows them to better target interventions.” A list of state coordinators is available on the CDC’s Web site at www2.cdc.gov/nccdphp/brfss2/coordinator.asp.

- Educate the public and other policymakers about the potential threat of diabetic retinopathy to the medical and financial health of your state. “Elected officials, by design, have a bully pulpit they can use to make these issues known,” said David Hoffman, chair of the Policy Committee of the National Association of Chronic Disease Directors.

- Propose legislation that empowers public health agencies to address the issue. “Public health agencies need resources and the authority to promote prevention, both primary prevention—preventing the disease in the first place—and secondary prevention, preventing complications of the disease,” Hoffman added.

- Encourage medical professionals to use an electronic diabetes registry that keeps track of all recommended screening tests for individuals with diabetes. During patient visits, the system reminds doctors what tests are needed and helps ensure all screenings are done each year; which helps reduce complications. Software can be used in individual doctors’ offices or a program can be implemented across an entire state. A trial called The Vermont Diabetes Information System, which electronically links participating laboratories and doctors’ offices to make it easier to keep track of results, is under way.

- Coordinate existing programs to increase the awareness of the importance of eye care, such as cardiovascular programs, maternal and child health and injury prevention. Many of these programs already have funding for eye care, but they are not focused on vision goals and potential enhancement efforts. Better coordination could increase their effectiveness.