



Oral, Eye and Foot Complications of Diabetes

Eye Complications Report

Prepared for:

Division of Diabetes Translation
Programs Development Branch
Centers for Disease Control and Prevention

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I. Executive Summary

Diabetes is one of the most burdensome and costly chronic diseases of our time. In the United States, an estimated seventeen million people have diabetes and more than three quarters of a million people are newly diagnosed with diabetes each year. It is a condition in which the body is unable to either produce or use the hormone insulin, leading to elevated blood sugar levels and potentially serious complications. These complications are a significant cause of morbidity and mortality and are associated with the damage or failure of various organs such as the eyes, kidneys, and nerves. Poor glycemic control can lead to heart disease, stroke, blindness, kidney disease, amputations, and dental disease.

The Centers for Disease Control and Prevention (CDC) is dedicated to eliminating the preventable burden of diabetes in the United States. The Division of Diabetes Translation (DDT) works to achieve this mission by combining support for public health-oriented diabetes control programs (DCPs) with efforts to translate diabetes research findings into widespread clinical and public health practice. DCPs in all 50 States and in nine other jurisdictions are funded by DDT as a cornerstone of this strategy. Collectively, these DCPs compose the National Diabetes Control Program.

Under contract to CDC, ORC Macro conducted a literature review, an environmental scan, and formative research in eye complications of diabetes. Data collected from the literature review and environmental scan suggested specific audience segments on which to focus in the formative research. A theoretical framework was developed to assist in delineating the parameters of the research, formulating the informal interview questions, and interpreting findings. Studies show health disparities between racial and ethnic groups in the United States in the rate of diabetes and its associated complications. Certain racial and ethnic communities, including African Americans, suffer disproportionately compared with White populations. An emphasis on African Americans with diabetes and health professionals was selected by CDC for the formative research. For more information on the literature review and the environmental scan, see reports entitled *Literature Review of Oral, Eye and Foot Complications of Diabetes* (April, 2002) and *Environmental Scan for Eye Complications of Diabetes* (May, 2002).

In this effort, it was critical to solicit information from health professionals who not only have a stake in disseminating the potential materials developed by CDC, but also play a significant role in preventing and treating eye complications of diabetes in African Americans. With this in mind, data collection activities were conducted with certified diabetes educators (CDEs), eye care providers (ophthalmologists and optometrists), and other important stakeholders from key organizations addressing eye complications of diabetes.

Key Findings Relevant for Program/Intervention Planning

Content-Specific Participant's Knowledge, Attitudes, Beliefs and Behaviors

- Diabetes educators indicated familiarity with eye complications of diabetes, its asymptomatic nature and the perceived confusion among patients regarding blurry vision, changes in prescription and diabetic eye disease.
- In-depth interviewees noted the complexity of the combination of social, economic and lifestyle factors in listing the challenges faced by that African Americans with diabetes.
- Participants indicated their knowledge of the importance of nutrition/diet and exercise in prevention of diabetes and the delay of complications, with special attention at institutionalized populations (prisons for example). They also indicated that they regularly emphasize to their patients several self-management strategies with glucose control and annual dilated eye exams for prevention of diabetic eye disease (diabetic retinopathy, cataracts and glaucoma).
- Participants expressed very strong convictions regarding what they perceive are barriers/challenges that their patients face in relation to diabetes care: lack of adequate access to services and information about diabetes, competing demands within a household, low economic financial status, external locus of control and fatalism surrounding diabetes.
- Participants believed that every member of the diabetes care team has a role in improving and promoting healthy behaviors and in supporting the patient's diabetes care management.

“One of the things that I think is important with respect to that is to talk to African Americans. I remember when I was involved with the National Eye Health Education Program, I strongly emphasized to them you need to talk to the people who are involved, who you are trying to implement the program to. People want to know that they have input of optometrists, of ophthalmologists, primary care physician. Everybody involved should have input and the patients. Because they will tell you how they want to get the information so that it's understandable to them.”
Eye Care Professional

- Participants felt very strongly that it was their duty and moral obligation to address issues of concern of African Americans with diabetes. Many mentioned that they themselves, their parents, relatives or close friends were affected by the disease in many ways.
- Diabetes educators expressed their frustration with what they perceive is a limited role with regards to addressing eye complications: they can only conduct educational sessions and check in a follow up visit whether the recommended visit to the eye care practitioner took place.
- Diabetes educators also indicated that is easier for them to address the oral or foot complications with their patients than is with eye complications, mainly because they can give specific instructions for prevention that can be easily implemented once patients leave

the office (brush and floss their teeth; check their feet and wear protective socks or shoes respectively). Still, some diabetes educators still incorporate “doable” actions, such as taking nutritional supplements in preventing eye complications.

- Eye care professionals perceive that speaking about eye complications of diabetes induces more fear than oral or even foot complications, due to the stigma associated with blindness.

“There is one little difference. When you emphasize the fact [that] they’ll go blind, it’s amazing the way it will get their attention. They would rather have their arm cut off than go blind.”
Eye Care Professional

- Eye care professionals indicated that some times they are the first to recommend to the patient to check for diabetes, given the nature of their vision problems.
- A few participants across groups indicated their current efforts, and many more expressed their willingness to gather more information on complications of diabetes via several venues (Internet searches, calling information 1-800 numbers, requesting materials, participating in seminars or CME-credit activities, etc.).

Need for Materials

- Participants believed that there was a great need for culturally-appropriate materials addressing eye complications of diabetes in the African American population, as well as for all populations with diabetes. For African Americans specifically, participants also believed that the links between diabetes and high blood pressure and cardiovascular disease are to be heavily emphasized.

“In my practice one of the big factors is just the difference in the education about diabetes between the African-American and the White populations. A lot of my Caucasian diabetics have looked up stuff on the Internet. They’ve been reading books. They know what their blood sugar should be and they know exactly how they should be managing things and it just seems that a lot of the African-American population that do seem to have diabetes have no idea about what’s going on. No one has taken the time before to go over things with them.”
Eye Care Professional

- Participants also expressed great need for hands-on, visual educational materials that they could use with their clients. Participants stated that photos, short quizzes, or even better, a tool such as a visual model of a healthy eye and an eye with diabetic eye disease would be particularly helpful to them when attempting to educate their clients.

“I can definitely use more handouts. One handout that I have that I use has got a lot of words on it, way too many words on it for eye care. Whereas I have another one for foot care that has a lot more pictures, a lot more white space and less words.”
Eye Care Professional

Partnerships

- Participants believed that every stakeholder has a role in improving and promoting eye health of patients with diabetes. Participants felt that many stakeholders can participate in a continuous quality-improvement cycle; a series of steps designed to enhance processes leading to improved patient and program outcomes.

“And even more grassroots, I know some of the hospitals, when I was at Baptist, I had an ophthalmologist that did an awful lot of eye, diabetic eye problems. He was an African American and he was wonderful teacher. He would sit down with all of his colored pencils for all the stuff on his paper whatever he saw in the eye he would doodle. He would sit down there and talk with anybody. He would let me go in there and he would show me some, I used to work in the operating room and they have dual magnifiers when they do eye surgery so a second person can look through and see what the surgeon is looking at.”
Certified Diabetes Educator

- Participants stated that they used materials from CDC and the U.S. Department of Health and Human Services to educate African Americans about eye complications of diabetes. The American Diabetes Association, Eli Lilly & Co., Pritchard and Hall, and the Lions Club were also mentioned as authoring agencies of resources used. Respondents mentioned that they referred to print materials, Web sites, and visual models in their educational efforts.
- Certified diabetes educators stated that they would collaborate with some specific national organizations including CDC, NIH (particularly NIDDK), the American Diabetes Association, the American Academy of Ophthalmology, and the National Federation of the Blind.
- A few specific resources were mentioned by stakeholders. *Diabetes-Sight.org*, a patient- and provider-focused website sponsored by Prevent Blindness America providing information for the prevention of vision loss from diabetes, was cited. The *Eye Care America Diabetes Project*, a public service project sponsored by the Foundation of the American Academy of Ophthalmology providing educational materials and referral services for persons with diabetes, was noted. Materials such as posters and brochures from the National Eye Institute’s *National Eye Health Education Program* were also mentioned.
- Participants indicated the merit of programs that involve partnerships between minority faith- and community-based organizations and health care facilities in a collaborative effort to address cultural needs of the African American population. Churches, health fairs, barbershops, community centers, adult day centers, were repeatedly mentioned as places/opportunities to effectively reach this population.

“Well, organizations, I mean, I still think of local churches. I just think that there’s not anybody in the African-American community that can have more influence than a trusted minister in a church to reach his parishioners. There are so many of the churches that my patients tell me about now that have health committees and health fairs and all of these kinds of things. If a church had a knowledgeable nurse or dietician in it, then oftentimes that’s an in-road

for the message to start getting out there about taking care and preventing complications.”
Certified Diabetes Educator

Role of CDC

- Participants envision CDC as a strong organization with which to collaborate in the effort to educate African Americans about eye complications of diabetes.
- Nevertheless, participants were not familiar with many of CDC’s existing public education resources for diabetes (although the National Diabetes Education Program and the Flu Campaign were identified as examples to follow).
- Participants believed that CDC should take a more active role in disseminating/distributing no-cost educational information about diabetes and eye complications.
- Several eye care professionals noted that CDC will need to build trust within the African American population for this type of campaign to be successful, and referred to the Tuskegee study and the distrust of African Americans associated with health-related studies.

Recommendations for Program/Intervention Planning

Several important findings have emerged as a result of this formative research, as discussed above. Stemming from that groundwork, the recommendations listed in the report are intended to guide future activities towards message development and dissemination of information about eye complications of diabetes among African Americans. A selection of these recommendations follow:

- Eye care providers stated that CDC should solicit the mass media and disseminate public service announcements regarding eye complications of diabetes through multiple channels including radio, television and print sources. The use of a celebrity spokesperson was strongly suggested in this approach. Participants mentioned Jackie Robinson, Gladys Knight, and Halle Berry as well-recognized African Americans with diabetes that could serve in the role of spokesperson.

“I was glad, in fact almost euphoric, at the onset of this discussion when you mentioned CDCP, Centers for Disease Control and Prevention. This is what care is all about, not only control but prevention also. As far as the preventive aspect is concerned, I think it’s important to get the diabetic population educated and empowered and one of the ways that it can be done efficiently is through the mass media. We don’t want to have these things just on the health channel. You want them on channel 2. You want to get charismatic people involved. We don’t have Magic Johnson for diabetes. We need someone like that.”

- Participants recommended incorporating information about proper nutrition habits in a culturally-appropriate way with cultural sensitivity with regards to body image, food preferences, meal preparation, and ethnic beliefs (supplements, herbal medicines, complementary medicine).
- Diabetes educators recommended to CDC to develop a community tool kit with posters, videos, written materials, screening tools, etc. for distribution to diabetes care professionals.
- Participants indicated that patient education materials should be written for lower literacy levels and should be highly visual, graphically depicted, with medium- to large-size font. Photos should be appropriate to the African-American population.
- Participants recommended the use of multiple outlets to deliver information to patients and diabetes care professionals (eye care providers and diabetes educators). Hands-on materials, videos, models, color pictures, flipcharts and other visual educational materials were mentioned as very helpful for diabetes care professionals to use with their patients. Seminars at professional conferences, CME courses, CD-ROMs, interactive modules and guides, and handouts are more suitable for the professional development of eye care providers and diabetes educators.