Patient Adherence to Guidelines for Diabetes Eye Care: Results from the Diabetic Eye Disease Follow-Up Study

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ABSTRACT

Early detection and treatment of diabetic eye disease can prevent blindness, yet many persons with diabetes lack regular eye care. This study followed 569 people with diabetes participating in blindness prevention programs during 1985 through 1987; it was found that 35% of subjects received dilated eye examinations before entering the programs, in comparison with 60% afterward. About 85% of participants referred for proliferative retinopathy treatment began such treatment, and, of these, 85% completed treatment. A lack of knowledge about the disease and limited finances were primary reasons for nonadherence. To improve the effectiveness of prevention programs, eye care providers and program staff must strive to eliminate these educational and financial barriers. (*Am J Public Health.* 1994;84: 1669–1671)

Introduction

Diabetes is a leading cause of blindness in US adults.[1] Laser therapy applied to advanced diabetic proliferative retinopathy reduces the risk of severe vision loss by 50% or more.[2] Blindness prevention guidelines emphasize early detection of diabetic eye disease.[3–9] Recent studies indicate, however, that about a third of people with diabetes have never had ophthalmologic examinations and that more than half of these individuals have eye disease.[10,11] To improve the eye care of diabetic persons and prevent blindness, the Centers for Disease Control and Prevention (CDC) has worked with 27 state health departments to develop and implement blindness prevention programs.* Program staff have identified persons with diabetes who have not had a dilated eye examination within the previous year, have examined them to detect eye disease, and have educated them about the need for annual examinations and adherence to treatment recommendations. Here, we summarize the findings of the Diabetic Eye Disease Follow-up Study, which was designed to evaluate and improve the effectiveness of these state programs.

Methods

In 1988, the CDC requested proposals for participation in the Diabetic Eye Disease Follow-up Study from among the 10 state blindness prevention programs that had operated in the United States prior to 1987. Proposals were accepted from programs that had served at least 50 persons with diabetes before October 1, 1986, and were able to track these individuals. Four programs were eligible, and all were approved for funding by a CDC technical review committee. The study was approved by a CDC institutional review board.

Between 1988 and 1990, the study assessed the programs described in the Appendix. Between 1985 and 1987, 2106 people participated in the programs. Of these, we followed 569 individuals from a probability sample of Whites, Blacks, and Hispanics and a census of people from other racial/ethnic groups for 2 to 5 years. Nonparticipants were not identified or followed.

To select the sample, we employed stratified random sampling and used program records to define strata based on geographic location, urgency of treatment, and racial/ethnic group. Program participants in each location (i.e., Minnesota, Florida, Maryland, the eastern plains of Colorado, and inner-city Denver) were categorized into four groups by urgency of recommended treatment as defined by the clinical judgment of individual eye care specialists. Participants diagnosed with diabetic eye disease that required immediate treatment constituted the first group. Participants with diabetic eye disease that required reexamination in less than 1 year but not immediately composed the second group. Participants without diabetic eye disease who were

*CDC now works with 40 state and territorial health departments. Rather than provide eye care services, current programs concentrate on core public health functions (e.g., surveillance, quality assurance, access).

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TABLE 1—Racial/Ethnic Characteristics of the US Diabetic Population, Program Participants, Individuals Selected for Study, Study Participants, and Subjects with Complete Medical Records

	White, %	Black, %	Hispanic, %	Other, %
US diabetic population (n = 4 778 000)	70.8	19.4	7.3	2.5
Program participants (n = 2106)	65.1	22.5	10.8	1.6[a]
Selected sample (n = 569)[b]	61.0	23.9	11.1	4.0
Completed interview (n = 414)	59.4	25.6	12.6	2.4
Complete medical record (n = 336)[c]	62.8	23.8	11.6	1.8

[a]Determined by use of program records. When interview data were used to determine racial/ethnic category, 10 of these individuals were later reassigned to the Black, White, or Hispanic category (the selected sample reflects this reassignment).
[b]One person was dropped from the sample because we were unable to definitively classify this individual by racial/ethnic category.
[c]The population of persons with diabetes who received a diagnostic examination and who had information recorded on the medical record abstraction form. These data were used to calculate treatment initiation and completion rates.

recommended for routine reexamination in 1 year constituted the third group. Finally, the fourth group included participants not classifiable by urgency of treatment. Individuals within each geographic area and group were then further stratified by racial/ethnic status. Within each area, all persons in the first group were selected for study (n = 172) to allow us to calculate treatment initiation and completion rates. The other groups were sampled to match the proportion of Blacks, Whites, and Hispanics in the first group.

Diabetic Eye Disease Follow-up Study investigators sent information to potential respondents, explaining the study's purpose and asking for permission to review medical records. Within 2 weeks, interviewers called subjects to request permission for a telephone interview. Interviewers made five attempts to contact each subject by telephone, made up to three visits to the subject's home, and, as a final attempt, sent the subject a questionnaire by mail. The 62-item, 20-minute questionnaire covered topics such as eye care history, knowledge, and barriers. Program eye evaluation records were then abstracted. If a medical release form was signed, the abstractor reviewed records from the subject's most recent eye care visit. The abstractor recorded the results of recommended treatment and reasons for not initiating treatment.

We employed various quality control procedures and used SUDAAN software to calculate proportions and standard errors and to conduct logistic regression analysis.[12] We used statistical weighting (corrected for nonresponse/lost to follow-up) to permit extrapolation to the total population of program participants.

Results

Four hundred forty-nine (79%) of the 569 subjects were contacted (complete medical records were obtained for 336 individuals, and interviews were completed for 414). One hundred twenty people (21%) were not contacted (74 had died, and 46 could not be reached).

Participants were more likely than the general diabetic population to be female, to use insulin, to be overweight, and to be financially disadvantaged (data not shown). They were also more likely to be Black or Hispanic (Table 1). The racial/ethnic status of persons who completed the interview or had complete medical records was not substantially different from that of all program participants.

We first determined the proportion of program participants initiating and completing treatment. As a result of program participation, 3% of persons were diagnosed with proliferative retinopathy, of whom 70% were referred for treatment. Treatment was initiated by 85% of the subjects referred, and, of these individuals, 85% completed the treatment. Of participants diagnosed with nonproliferative retinopathy, 5% were referred for treatment. Of the subjects referred, 48% initiated treatment, and of these individuals, 82% completed treatment.

Of the 74 individuals referred for treatment for proliferative or nonproliferative retinopathy, 25 (34%) did not initiate treatment within 1 year. Eye care records revealed that 12 (49%) of the 25 who did not initiate treatment were under the care of a doctor and were awaiting treatment; 6 (24%) persons indicated that they did not want treatment, and 1 (4%) had died. Reasons for not initiating treatment were not given in records for the remaining 6 subjects.

Second, we assessed the proportion of subjects who received annual examinations after joining the program. Sixty percent of interviewed participants reported receiving an annual examination during the year preceding the interview. Logistic regression analysis showed that proliferative and preproliferative retinopathy detected during the program's diagnostic examination strongly predicted later adherence to annual examination (odds ratio [OR] = 5.7, 95% confidence interval [CI] = 3.7, 8.8, for proliferative retinopathy; OR = 12.4, 95% CI = 7.0, 22.0, for preproliferative retinopathy). Also, the more recently patients participated in a blindness prevention program, the more likely they were to have annual examinations ($P = .002$).

Those who had not received an annual examination offered numerous explanations. The two most common reasons—given by approximately 60% of the respondents—were that they could not pay for an examination and that they had no visual symptoms.

Discussion

Evidence suggests that people who have never received eye care have difficulty adhering to eye care recommendations.[13] Only 35% of our subjects had received a dilated eye examination during the year prior to enrolling in a blindness prevention program. Despite this, 85% of program participants recommended for proliferative retinopathy treatment initiated and completed treatment. Furthermore, they continued receiving eye examinations. Two to 5 years after joining a program, 60% of participants reported having received an eye examination within the previous year. Indeed, diagnosis of retinopathy during program participation and recency of program participation strongly predict adherence to annual eye examination.

Given the effectiveness of retinopathy treatment, nonadherence to treatment recommendations signals a seriously

flawed system. Programs can improve this system by identifying people who do not initiate or complete retinopathy treatment and the reasons why they do not. Eye care providers should aggressively pursue and record the reasons for nonadherence and work with prevention program personnel to eliminate treatment barriers. Program personnel should consider establishing an annual examination reminder system to advise people with diabetes that retinopathy is often a silent disease and that annual examinations are important even when no visual symptoms are evident. Moreover, reminders should offer people information about low-cost services and other strategies to overcome financial barriers. □

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APPENDIX—Descriptions of the Four Blindness Prevention Programs Used in the Study

Maryland

The Maryland program employed a two-person team from the Johns Hopkins Diabetes Center to conduct eye disease screenings at 14 sites throughout a wide geographic area. Free screenings were conducted at community health centers, hospitals, local health departments, and local American Diabetes Association chapters. Those who had not received a dilated eye examination during the previous year were asked to identify themselves by responding to newspaper and public service announcements and to promotions at local diabetes education classes and American Diabetes Association chapter meetings. Identified persons were then recruited for nonmydriatic fundus photography of each eye, visual acuity testing, tonometry, blood pressure measurement, and eye care education. Seven hundred seventy-three persons with diabetes participated between 1985 and 1987. The photographs were read by a retinal specialist at Johns Hopkins University. Patients were referred to an ophthalmologist if proliferative retinopathy was detected. All other patients were urged to seek diagnostic examinations.

Florida

People with diabetes were examined for eye disease at two Pinellas County public health units located in St. Petersburg and Clearwater. This program was available to public health clinic clients with diabetes who had not received a diagnostic eye examination within 12 months prior to the screening examination. Local print, radio, and television media participated in announcing the availability of screening services for public health clients. Five hundred seven persons with diabetes participated between 1985 and 1987. The examination included visual acuity testing, intraocular pressure measurements, nonmydriatic retinal photographs of both eyes, and eye care education. Retinal photographs were sent to a university-based school of ophthalmology for evaluation. Depending on ophthalmologists' judgments of the severity of disease, patients were referred either for a confirmatory diagnostic examination or for routine follow-up within 1 year.

Minnesota

An epidemiologic study in Marshall enumerated all individuals with physician-defined diabetes who used the local medical care system (n = 533). Those who reported never having had an ophthalmologic examination (n = 172) were referred for a free eye examination at a local ophthalmologist's office. One hundred forty-five persons (85%) received the examination, which included visual acuity testing, tonometry, dilated funduscopic examinations, and mydriatic fundus photography. If proliferative retinopathy with high-risk characteristics was detected by the ophthalmologist, patients were given immediate treatment. Those with less serious eye disease were recommended for follow-up. Patients were also given eye care education at a community-based education program located at the same health care center as the ophthalmologist's office.

Colorado

The Colorado program targeted residents of inner-city Denver and the rural eastern plains. The inner-city residents generally have low incomes and traditionally do not use prev ntive health practices for diabetes control. Diabetes status was determined by reviewing medical and billing records of a major inner-city medical facility. The medical charts of all persons with diabetes were then identified by affixing brightly colored stickers to the patient's problem list. Health care providers were asked to use these charts to identify persons with diabetes and to refer those who had not had an eye examination during the past year to the medical facility's eye clinic. Residents of the eastern plains are dispersed throughout a large geographic area that has limited ophthalmologic services. These program participants were recruited through public announcements and by asking primary care physicians and health facilities to refer persons with diabetes to the program. Program publicity included announcements via radio and newspapers, hospitals, and pharmacies. Announcements emphasized that persons with diabetes who had not had a dilated eye examination during the past year were eligible for the program. All recruited persons were examined by an ophthalmologist who was in private practice or was temporarily located in a special clinic. Six hundred eighty-five persons with diabetes participated in the program between 1985 and 1987.