

PERSONALIZED FOLLOW-UP INCREASES RETURN RATE AT URBAN EYE DISEASE SCREENING CLINICS FOR AFRICAN AMERICANS WITH DIABETES: RESULTS OF A RANDOMIZED TRIAL

Objective: To evaluate the effectiveness of using personalized followup, as compared to reminder letters, in increasing return rates at urban eye disease screening clinics for African Americans with diabetes, and to identify factors predictive of the patient's likelihood of returning for annual follow-up exams.

Research Design and Methods: All patients attending free community-based retinopathy screening clinics who were advised to return in one year for another diabetes eye evaluation (DEE) were randomized to standard or personalized follow-up interventions. Patients in the standard follow-up group received reminder letters a month before it was time to return for their next annual DEE. Patients in the intensive personalized intervention also received the letters, but those patients who did not call for an appointment within 10 days received a phone call from project staff, encouraging them to return for a DEE.

Results: One hundred thirty-two African Americans with diabetes were randomized to one of the 2 treatments. The return rate for the intensive, personalized follow-up group was 66%, significantly ($P=.001$) higher than the 35% return rate for the standard follow-up group.

Conclusion: This study demonstrated the efficacy of personal contact by telephone in improving return rates for annual DEEs in this population of patients. This finding is consistent with one of the key design principles of the project, which was to establish credible personal relationships with community leaders and patients as a means to maximize the utilization of the eye screening clinics. (*Ethn Dis.* 2003;13:40-46)

Key Words: Behavior, Diabetes Mellitus, Education

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INTRODUCTION

The efficacy of early detection and treatment of diabetic retinopathy was established over 15 years ago.^{1,2} Although regular diabetes eye evaluations (DEE) by eye care specialists are recommended by the American Diabetes Association,³ a substantial number of patients with diabetes do not receive a DEE on a regular basis,⁴⁻⁶ especially in disadvantaged urban communities.⁷⁻⁸ Regular examinations may be especially important for African Americans with diabetes. The rate of diabetes in African Americans has tripled in the last 30 years, resulting in a prevalence rate of diagnosed diabetes in African Americans that is 1.4 to 2.3 times greater than that for Caucasians.^{9,10} Furthermore, some recent studies have suggested that diabetic African Americans may suffer more severe diabetic retinopathy and loss of vision, compared to their White diabetic counterparts.¹¹⁻¹³

To be effective, a DEE must be completed on a regular basis. Recent studies examining various reminder systems to promote annual DEEs found that the effectiveness of mailed reminders tends to be modest and short-lived.¹⁴⁻¹⁵ Also, the impact of reminder systems varies with the patient population, the medical systems in which the reminders are implemented, visit inter-

vals, and geographic region.¹⁶⁻¹⁸ One recent study in a large managed care system found that using multiple mailed reminders only resulted in small increases in return rates for DEEs.¹⁹ However, researchers in another study²⁰ employing a health education intervention designed specifically for African Americans with diabetes, achieved a 54.7% return rate (within 6 months of the intervention), compared to a return rate of 27.3% for the control group. The intervention used in the above study involved mailing a culturally tailored brochure and video tape to participants immediately after randomization, followed a week later by a phone call using a semi-structured protocol aimed at helping the patient make an informed decision about obtaining an ophthalmic examination.

The purpose of the present study was to evaluate the effectiveness of 2 reminder systems for one-year follow-up DEE in a group of urban African-American patients with diabetes and to identify factors predictive of the patient's likelihood of returning for annual DEEs.

METHODS

Screening Clinics

The study reported here was part of a project conducted in southeastern Michigan from 1995 through 1999^{21,22} that was designed to evaluate the effectiveness of free, community-based, culture-specific, eye-disease screening clin-

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“... some recent studies have suggested that diabetic African Americans may suffer more severe diabetic retinopathy and loss of vision, compared to their White diabetic counterparts.”¹¹⁻¹³

ics for urban African Americans with diabetes. Key features of the larger project included: conducting focus groups to identify the cultural meanings and perceptions of the target audience regarding diabetes;²³ collaborating with credible local community organizations, such as churches, the Urban League, and Afro-centric human service agencies, in order to reach the target population with both health messages and screening services (ie, all clinics were co-sponsored by a collaborating community-based agency);²⁴⁻²⁸ and making an aggressive effort to ensure that patients identified by screening as needing further treatment were actually treated.

The availability of free eye screenings was publicized through local newspapers and radio stations with a high penetration rate among the target audience. Culturally tailored posters, flyers, and announcements (eg, posters featuring African Americans and materials using yellow, green, red, and black colors, which are viewed as Afro-centric) were developed and distributed. Stationery featuring Kente cloth, an African print, was used for reminder cards and descriptive brochures. A more complete discussion of the culturally specific approach employed can be found in an earlier paper describing the project.²¹ These materials were distributed by collaborating community-based organizations, as well as at health fairs and sim-

ilar events. Patients interested in having their eyes screened were encouraged to call a toll free number and make an appointment to attend one of the upcoming eye clinics.

Study Population

The participants in this study were diabetic adults residing in the greater Detroit metropolitan area, who were seen at 9 community-based eye screening clinics held at 8 different locations, and then advised to return in one year for a follow-up DEE. The patients were randomized for intervention into 2 categories, designated as “personalized” and “standard.” Because the intervention was designed to be culturally specific to African Americans with diabetes, the 132 African-American patients who were randomized are the focus of this report.

Study Design

Regardless of ethnicity, all persons who attended the screening clinics received a dilated eye exam by a volunteer community-based ophthalmologist. The eye exam included visual acuity, intra-ocular pressure, and a fundus examination through a dilated pupil. All ophthalmologists recorded their findings on a standardized protocol, developed by project staff, with precise definitions for each condition. For example, the definition of glaucoma was intra-ocular pressure ≥ 30 mm Hg. Immediately after receiving the dilated eye exam, the patient was told the results by the examining ophthalmologist.

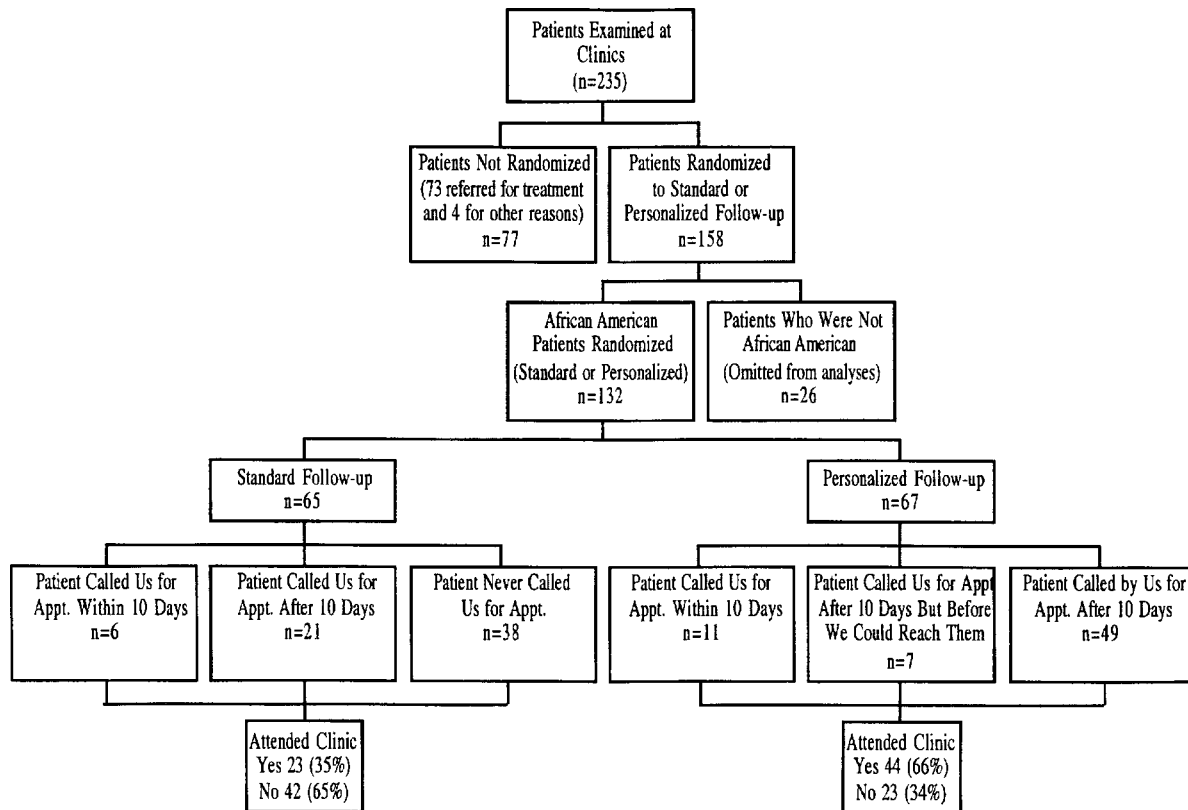
Based on the results of the eye examination, patients were assigned to one of 3 categories. Category one comprised patients with one or more of the following: proliferative diabetic retinopathy, vitreous hemorrhage, macular edema, or glaucoma; these patients were advised to be seen immediately (ie, in less than 30 days). Patients with moderate to severe non-proliferative diabetic retinopathy, or who were suspect for glaucoma, were assigned to category 2 and advised to be

seen soon (in less than 3 months). Category three comprised patients with a normal exam, or with one or more of the following: mild non-proliferative (background) diabetic retinopathy, cataracts, macular drusen/pigment changes, who were advised to return in a year for another diabetes eye evaluation (DEE).

Patients in category 3 were randomized to either a standard or intensive personalized follow-up intervention. The following year, these patients were sent a letter at least one month before the date scheduled for the next annual DEE. The letter included information about the date, time, and location of the upcoming eye clinic, and encouraged the patient to call a toll free number to make an appointment. Patients in the standard follow-up group received no further reminders about the upcoming clinic.

Patients randomized to the intensive personalized follow-up group received a phone call if they did not call for an appointment for a DEE within 10 days of the date the letters were sent. During this call, the patient was reminded that it was time for the annual DEE and cordially invited to make an appointment for the upcoming clinic. The beginning of the call was standardized, with the staff person saying, “We are calling because we mailed you a letter about your annual eye exam and have not heard from you.” However, because the interaction was intended to be personalized, the discussion from that point on was responsive to the patient’s individual concerns, and addressed any personal barriers to his or her making a return visit. In addition, key messages were included in every phone call, ie, “diabetes eye disease can lead to vision loss and blindness if it remains undetected and untreated. Your health matters, and we will do all we can to help you attend a screening clinic.” If patients indicated that they would not be able to attend the next available clinic, they were offered appointments at later clinics until

Table 1. Results of standard versus personalized follow-up intervention on clinic show rate



a convenient date could be set. If the patient needed transportation, it was arranged for by project staff.

Definition of Return for an Annual DEE

Screening clinics were held in the spring and fall of the year. Patients who were first examined during the spring or fall of one year were considered to have returned for an annual DEE when they attended a clinic during the same season of the following year.

Statistical Methods

T tests were used to compare means of the continuous variables for the randomized categorization, and of the return visit outcome variable. Yates-corrected chi-square tests were used to compare percentages for 2x2 tables; Pearson chi-square tests were used for

2xK tables (where K>2). Stepwise logistic regression was used for the final analyses of the return to clinic outcome. Variables previously found to be significant in univariate tests were used to predict return to clinic.

RESULTS

Two hundred thirty-five patients attended the clinics included in this segment of the study. Categories one and two comprised 73 patients; these patients were referred for treatment and were therefore not randomized for recall to annual exams. Four other patients were not randomized for individual reasons. One hundred fifty-eight patients of various ethnicities were randomized into the 2 intervention groups, standard and personalized. Since this study fo-

cused on a culturally specific intervention, the 26 Caucasian and Latino patients advised to return for an annual DEE were not included in our analyses; rather, this report focuses on the 132 remaining African-American patients (see Table 1).

A description of the demographic and medical information collected at the initial screening is provided for the study sample by assigned condition in Table 2. Randomization produced similar demographic and medical history characteristics in the 2 intervention groups. Study participants tended to be middle-aged (average age of 55 years), female (62%), and to have had diagnosed diabetes for an average of 7.9 years. Almost all reported having type 2 diabetes, and 51% were being treated with insulin. Only 42% of the participants had ever attended diabetes edu-

Table 2. Demographic and medical history: characteristics of study participants

Variable	Personalized Follow-up Group* (N=67)	Standard Follow-up Group* (N=65)
<i>Demographic</i>		
Mean age in years	55.0	54.5
% Female	70.1	53.8
% Education <12 years	25.8	35.4
<i>Biological</i>		
% Mean body mass index (kg/m ²)	33.2	32.0
Glycosylated hemoglobin (%)† (normal 4%–8%)	11.8	12.2
<i>Diabetes</i>		
% Type 2 diabetes	98.5	100.0
% Currently using insulin	47.8	52.3
Mean yrs since diagnosis	8.7	7.1
% Ever attended a diabetes education class	46.2	37.7
% Self-rated understanding of diabetes “good” or higher	81.5	73.8
% Told by physician that they had one or more diabetes complications	27.3	29.2
<i>Other health</i>		
% Currently smoking	27.3	30.2
% History of heart attack	4.5	13.8
% History of stroke	9.1	7.8
<i>Eye-care</i>		
Ever had an eye-exam by an ophthalmologist	59.4	59.4
Had eye exam by an ophthalmologist during past year	24.2	26.2
<i>Source of information about clinics</i>		
% Community agency	57.6	39.1
% News media	13.6	12.5
% Health professional	12.1	15.6
% Friend/relative/support group	9.1	23.4
% Other	7.6	9.4

* There were no statistically significant ($P < .05$) differences between the 2 groups on any of the variables in this table.

† Glycosylated hemoglobin provides a measure of the average blood glucose level over the past 2–3 months. It is similar to, but has a different normal range than the hemoglobin A_{1c} assay which has now become the standard but was not when this study began.

cation classes, and about 40% had never had an ophthalmic eye exam. About 75% of the group had not seen an ophthalmologist in the past year for a DEE.

Follow-up return rates by group indicate a substantial advantage to the group receiving personalized contact (Tables 1 and 3). Within the personalized follow-up group, 66% returned for an annual follow-up examination, compared to only 35% of the standard follow-up group ($P = .001$, chi-square test).

Further univariate analyses were conducted to identify other factors predictive of the patient’s likelihood of returning for an annual DEE. The results of these analyses (Table 3) indicated that aside from the intervention itself, several additional factors differentiated return-

ers from non-returners. These factors included information source (non-returners tended to cite support groups or friends as the source from which they learned of the clinics, while returners tended to cite a collaborating community-based organization), and current smoking status (smokers were less likely to return.) Returners were more likely than non-returners to have reported ever having had an eye exam by an ophthalmologist. In addition, return rates varied by the sponsoring agency/site where the screening clinic took place. However, neither age, gender, years of schooling, attendance at diabetes education classes, years since diagnosis of diabetes, nor the presence of complications related to diabetes, were signifi-

cantly associated with annual return rates.

The intervention category and the other significant factors were included in stepwise logistic regression analyses to predict the likelihood of a return visit to the clinic. Results from the final logistic regression model are shown in Table 4. Among the factors identified in the univariate analyses, only smoking status did not enter the stepwise logistic equation. As expected, the first significant effect on the likelihood of returning was the intervention, with intensive followup improving the return rate. A history of having ever seen an ophthalmologist next entered the model, also with a positive influence on return. Finally, return rates were affected by both clinic loca-

Table 3. Univariate associations with returning for follow-up eye exam among screened African-American patients

Factor	%	P Value*
Intervention		
Intensive	65.7	.001
Standard	35.4	
Information source		
Community agency	65.1	.002
News media	47.1	
Health professional	55.6	
Friend/relative	14.3	
Other	36.4	
Eye exam by ophthalmologist: ever		
Yes	60.5	.013
No	36.5	
Eye exam: by ophthalmologist: past year		
Yes	63.6	ns
No	46.9	
Diabetes understanding		
Self-rated as "good" or better	54.1	ns
Self-rated as less than "good"	35.7	
Current smoking status		
Non-smoker	57.6	.034
Smoker	35.1	
Clinic sponsor/site (N=8)	Range: 0.0 to 64.0	.031
Age		
20 to 44 years	37.9	ns
45 to 64 years	50.7	
65 years or older	61.1	
Gender		
Female	53.7	ns
Male	46.0	

* Yates-corrected chi-square tests were used to compare percentages for 2x tables; Pearson chi-square tests were used for the 2xk tables (where k>2).

tion (some locations had higher return rates than others), and by the source from which the participant heard about the clinic. Patients were much less likely to return if they had only learned about the clinics from a support group, friends, other patients, or relatives.

Patients referred by a community agency were randomized more often to the intervention than to the standard care group (58% vs 39%). Moreover, referral source was a significant univariate predictor for return to clinic (Table 3), with those referred by community agencies having the highest return rate. However, a stratified analysis by community agency indicates that the effect of the intervention was similar to the overall group effect. Within the subset of patients referred by a community agency, 78.9% (30/38) of the intervention group returned, compared to 44.0% (11/25) of the control group ($P=.004$, Pearson's chi-square test). This finding indicates that any possible imbalance in allocation of community-referred subjects to the intervention group did not unduly affect the findings.

Table 4. Factors predictive of returning for annual diabetes retinal exam as determined by stepwise logistic regression analysis

Factor	Order of Entry into Equation	Odds Ratio	Results at Final Step 95% CI	P Value
Intensive (personal) follow-up	1	5.62	2.13, 14.86	.0006
Eye exam by ophthalmologist ever:	2	6.52	2.25, 18.93	.0005
Clinic location*	3	Range: .0005 to 13.4	—	(.02, .04, .04)
Clinic referral source†	4	Range: .07 to .97	—	(.04)
Nagelkerke R ² -value for model: 0.487				
Entrance into the model: $P=.05$				
Overall prediction of model — percent correctly predicted:				
— no timely return: 75.8% (47/62)				
— yes, timely return: 82.8% (53/64)				
— overall correct as predicted: 79.4% (100/126)				

* Odds ratios for clinic location are set relative to a single location. The range indicates the variability in likelihood of returning across locations. P values given are for the 3 clinic locations with significantly better return rates.

† Odds ratios for clinic information source (or how a patient initially heard about the screening clinics) are computed using a reference group of those who designated "other" (all other sources). The additional 4 categories are the sponsoring agency; the media (newspaper/radio/television); health professional (doctor/diabetes educator); and support group/friend/parent/relatives. Compared to the "other" group, those informed by support groups/friends/parents/relatives were significantly less likely to return: OR of 0.07, 95% CI=0.005, 0.85. P value is given for this support groups/friends/parents/relatives category.

The difference in impact of the 2 interventions was so marked that, after the first analysis of the data, it was decided that it would be unethical to continue randomization.

DISCUSSION

Effectiveness of the Intervention

This study demonstrates the power of personal phone calls to substantially improve the return rates for annual DEEs in this population of patients. The difference in impact of the 2 interventions was so marked that, after the first analysis of the data, it was decided that it would be unethical to continue randomization. All patients attending subsequent screening clinics received the personalized, follow-up intervention. Based on the experience of the follow-up calls, it appeared that it was the personal nature of the follow-up phone call that accounted for the improved return rates. However, this was not studied directly, eg, comparing the effectiveness of automated phone reminders vs personal phone calls. The hypothesis that the personal nature of the phone calls contributed significantly to their impact on return rates is supported by a number of factors. For example, the results of some large-scale studies^{14,15,19} found only modest, short-lived increases in return rates for DEEs when using multiple mailings, suggesting that the power of such impersonal reminders is limited.

Further supporting this hypothesis is the overall success of the interventions, since the project itself was tailored to meet the needs and characteristics of urban African Americans with diabetes²⁴⁻²⁹ and therefore required each aspect of the in-

tervention to be personalized. As the project was being introduced, several community leaders voiced the opinion that having a project sponsored by an academic medical center reduced, rather than enhanced, its credibility. Many African Americans are suspicious of the dominant institutions in this society, including universities and medical centers, especially when it comes to research.^{30,31} It soon became clear that in order for this project to succeed, credibility and trust had to be established by developing personal relationships with community leaders and, subsequently, with the patients in the study.^{24,25,29} The culturally specific approach used emphasized the importance of personal relationships in all aspects of the study.²¹ The fact that patients were called by people they knew and trusted appears to be largely responsible for the 66% return rate in the intervention group.

Other Predictors of Returning for an Eye Exam

Results from the univariate analyses and the logistic regression models indicated that patients with a history of ever having had an eye exam by an ophthalmologist were more likely to return for a follow-up annual DEE. This finding is not surprising since the frequency of past care is often predictive of the frequency of future care. The project team further improved follow-up rates by becoming affiliated with credible local organizations, and co-sponsoring the clinics. From among their five choices, most participants (48%) selected the local sponsoring agency as the source from which they learned of the screening clinics.

Study Limitations

Some of the characteristics of this study limit its generalizability to the entire diabetic population. This is a study of African Americans with diabetes living in an urban setting in southeastern Michigan. Although these patients may be similar to other African Americans

with diabetes living in urban settings, they are likely to differ in important respects from African Americans with diabetes living in rural settings. Also, this was a relatively educated group of patients with a substantial majority having completed high school. This fact suggests that this intervention is likely to be most effective among patients who are members of the middle class, and may be less effective in reaching patients in urban settings living at or below the poverty level.

SUMMARY

We are in a period of rapid technological change, especially in the area of computer/internet-related applications, while at the same time healthcare organizations are under significant pressure to reduce costs and make health care more efficient. The potential for more effective and efficient communication through the use of modern communication technology, such as the Internet, is intriguing.³²⁻³⁶ However, these study results should be viewed as cautionary, in that communication has both content and context. The way in which particular content is communicated conveys important messages about the sender's perceptions of, and attitude toward, the recipient. The use of the telephone to convey not only information, but also concern and caring for the patient, appears to have made this intervention effective. Personalized communication, of demonstrated efficacy, should be employed in the development of technology that can be used to support, but not replace, the relationship of patients and health professionals. Marshall McLuhan's prophetic words, "The medium is the message," may well hold true for health care.

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