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Vision is precious: a successful behavioral intervention to increase the rate of screening for diabetic retinopathy for inner-city adults

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Abstract

Purpose—This purpose of this report is to describe a successful telephone intervention to increase the rate of diabetic retinopathy screening, its implementation with English and Spanish speakers, and the characteristics of those who benefited most from the intervention.

Methods—Participants in the telephone group ($n = 305$) received a tailored intervention from trained health educators who were ethnically diverse and representative of the community. The main outcome for the randomized controlled study was documented receipt of a dilated fundus examination (DFE) within the 6-month study window. Exploratory analyses focused on examining the factors that contribute to receiving a DFE within 6 months for participants in the tailored telephone intervention using Pearson chi-square and logistic regression analysis.

Results—Participants in the telephone intervention who did not receive a DFE had significantly more documented steps in the behavioral process than those who did receive a DFE, and ethnic concordance was not significantly associated with a positive outcome DFE group. There was a negative association between the time spent building rapport and receipt of DFE. As time spent engaging in educational activities by telephone increased, the likelihood of receiving a DFE increased.

Conclusions—Though the telephone intervention was highly successful compared to the print intervention, these process results demonstrate the difficulties and challenges of conducting a tailored telephone intervention to improve rates of screening in an underserved, diverse urban community.

Retinopathy is a common eye problem for people with diabetes and if not treated early, it can lead to blindness. Diabetes is the leading cause of blindness for adults aged 20–74, and diabetic retinopathy causes up to 24,000 new cases of blindness each year.¹ In 2003, three million adults with diabetes reported visual impairment.² In the U.S. population, the number of adults 40 years and older with diabetic retinopathy is expected to increase from 4.1 million to 7.2 million by the year 2020.³

Screening for diabetic retinopathy is a crucial step in reducing blindness. Detecting and then treating diabetic eye disease can reduce the development of severe vision loss by an estimated 50–60%.^{1, 4} According to the Centers for Disease Control and Prevention,² diabetic retinopathy causes 12,000 to 24,000 new cases of blindness each year. The age-adjusted percent of annual dilated eye exams among adults with diabetes in the U.S. during 1994–2004 was only 61.9%.¹ Mukamel, Bresnick, Wang and Dickey⁵ found that only 16% of the 4410 of diabetic patients in their study received an annual screen in two consecutive years (1992 and 1993). Therefore, many individuals with diabetes are not screened regularly for retinopathy which is a preventable problem. Based on data from emerging studies that many with diabetes are not receiving regular dilated eye examinations, the American Diabetes Association continues to recommend that adults with type 2 diabetes receive a dilated eye examination shortly after diagnosis, annual dilated eye examinations from that point forward, and more frequent examinations if retinopathy is progressing.⁶

Ethnic minorities are at an increased risk for diabetes-related complications, including diabetic retinopathy.⁷ Certain racial and ethnic minority groups have higher rates of diabetic retinopathy and blindness compared to non-Hispanic Whites.^{8–9} There is an emerging body of literature on culturally-appropriate interventions to improve screening for retinopathy among adults with type 2 diabetes. Basch, Walker, Howard, Shamoon, and Zybert conducted a randomized trial of a multi-component health education intervention to increase ophthalmic examination rates among low-income African Americans ($N = 280$) with diabetes.¹⁰ The intervention was associated with a large and significant increase in ophthalmic examinations for the telephone intervention group, where the examination rate was 54.7%, compared to 27.3% in the standard care group after a 6-month intervention—a doubling of the screening rate.

Diabetic retinopathy and eye complications can be reduced or prevented with routine screening to detect problems early. With this knowledge, a behavioral intervention was designed for a multi-ethnic population in English and Spanish to increase the rate of screening for diabetic retinopathy by dilated fundus examination (DFE). Given the important role of culture in health outcomes¹¹, the intervention was developed to be culturally sensitive based on the literature as well as those delivering the intervention.¹² As such, health educators were culturally similar to participants and had a connection to participants' values, background, language, and environmental surroundings. These factors facilitated the delivery of the intervention.

In a randomized controlled study, the Vision is Precious (VIP) tailored telephone intervention increased the rate of screening by 74% compared to the print intervention during a six-month period for urban, minority participants who had not had a DFE in over one year.¹³ This purpose of this report is to provide a detailed description of the successful VIP intervention in English and Spanish, its implementation, and characteristics of those who benefited most from the intervention. The goal is to facilitate its replication in other similar settings.

Methods

The purpose of the main VIP study was to test the hypothesis that a tailored telephone intervention in Spanish and English, as preferred by participants, would result in a higher rate of screening for diabetic retinopathy than a standard print intervention among an ethnically diverse sample of 598 adults with diabetes living in the New York area. In addition, the research team assessed differences in rates of diabetic retinopathy screening by demographic and background characteristics (e.g., race, ethnicity, gender, English vs. Spanish speaking) and changes in diabetes-related risk perceptions over time. The VIP project was completed between 2001 and 2006; a full description of the study methods and results can be found elsewhere.¹³

The development and implementation of the intervention was broadly based on the Precede-Proceed model for health promotion^{14,15} focusing on the predisposing, reinforcing and enabling factors that may influence a health behavior, such as obtaining a dilated eye exam. Elements of the Transtheoretical model's stages/readiness for change¹⁶ and motivational interviewing (MI)¹⁷ techniques informed the protocol for health behavior counseling techniques. The methods for the VIP randomized controlled trial and details about the print intervention are published in the main results paper.¹³ In the next section, a comprehensive report of the successful telephonic intervention is presented.

Tailored Telephone Intervention

Participants in the telephone group ($n = 305$) received a tailored intervention from trained health educators who were ethnically diverse and representative of the community. The health educators delivered the intervention in English or Spanish. The telephone script and all educational materials were translated into Spanish. The telephonic intervention was delivered in Spanish to Spanish speaking participants as needed. In addition, the intervention was tailored according to the individual's needs; i.e., the telephone calls were patient-centered and the discussions were tailored based on the topic or issue the patient wanted to discuss at that time. The health educators had a minimum of a bachelor's degree in generally a social science (e.g., psychology, sociology), and they received approximately 20 hours of training by a nurse certified diabetes educator (CDE), including participation in a series of diabetes self-management education classes. In addition, health educators received ongoing training including: participation in weekly case management meetings to discuss intervention implementation, fidelity to protocol, and individual participant issues; a periodic journal club to review pertinent topics; and guest lectures from multi-disciplinary diabetes clinicians. While the health educators were exposed to the principles of MI as applied to promotion of retinopathy screening, they were not required to adhere to a strict protocol for implementation of MI techniques.¹⁸

Participants could receive up to seven telephone calls within the six-month period; telephone calls ceased when a participant indicated they had received a DFE. During the intervention phone calls health educators used intervention talking points to establish rapport with individuals and deliver the intervention. Patients were interviewed to uncover issues and barriers that might either motivate them or prevent them from going for a DFE. Attempts were made to engage all participants with targeted self-management strategies and DFE

education, and they were encouraged to make an appointment for a DFE if they indicated they were ready to change.

Generally, health educators discussed diabetes-related eye problems, such as retinopathy, the recommended standard of eye care for people with diabetes, key elements of a DFE, symptoms of retinopathy, and the importance of screening and early treatment for such problems. Health educators also covered prevention of diabetes eye problems and how poor diabetes control or blood pressure control can negatively impact the eyes and retina.

Through identifying barriers to getting a DFE and problem solving, along with motivational interviewing techniques and an assessment of stage of change¹⁶, intervention telephone calls were tailored to participant's needs. During these calls, health educators engaged in culturally-sensitive dialog, while helping participants navigate DFE barriers, such as fear of finding an eye problem, lack of time for the exam, or costs in terms of the exam or time lost from work. Culturally sensitive dialog refers to the health educators' ability to connect with participants in a culturally-relevant manner. More specifically, the health educators were culturally similar to participants in terms of neighborhood, culture, and language. As a result, health educators were sensitive to and familiar with participants' cultural context. This sense of familiarity facilitated the ability to frame the intervention content according to experiences with individuals in the community. This approach facilitated one-on-one dialog, but may not have worked as well in an automated medium or group setting.

The health educators' goals were to: educate participants about diabetes-related eye health; help participants navigate barriers and obstacles to getting a DFE; increase the likelihood that participants would make a DFE appointment or ask their provider for a referral for a DFE; and finally, complete the appointment to have a DFE. Examples of the intervention talking points used to engage study participants are presented in Table 1.

At the end of each phone call, health educators attempted to set a date for the next phone call in order to give participants time to reflect on the material covered during the conversation. During the subsequent phone call, health educators verified whether the plan to get a referral, make an appointment or complete an appointment was made. Only those who indicated they had not yet received a DFE were re-contacted. Participants in the telephone intervention group could receive a maximum of seven calls over a six-month period. The content of each phone call built on the issues discussed in the previous phone call and the participants' stage or readiness for change in terms of getting a dilated eye exam.

Participant's readiness to change was assessed as to whether the s/he was in the precontemplation, contemplation, preparation or action stage for going for a dilated eye examination, considering that none of them had received a DFE in the last year.¹⁶ During telephone calls participants' responses to the dialogue helped health educators estimate stage of change (see Table 1). This was done so that the intervention dialog would be tailored to match the participant's readiness to change the behavior. More specifically, those who did not want to talk about diabetes and the eyes were assessed as being in the precontemplation stage. Those who knew about diabetes-related eye problems or who were thinking about going in for a DFE were in the contemplation stage. Those who made a verbal commitment

to make an appointment for a DFE were coded as being in the preparation stage, while those who verbally indicated having made an appointment for a DFE were considered to be in the action stage. For those in the precontemplation stage, the health educators' motivational task was focused on increasing participants' perception of diabetes-related risk of eye problems. Health educators discussed the risk associated with not changing diabetes self-care behavior, such as going for a DFE. They attempted to strengthen self-efficacy for participants in the contemplation stage by focusing on rationale for having a DFE as a prevention for vision loss and eye problems associated with diabetes. Health educators assisted those in the preparation stage with determining the best course of action for making change, such as making the appointment for a DFE or getting a referral; those in the action stage were assisted with the steps required to complete the behavior of getting screened for retinopathy.

After each phone call, health educators coded the exchange and completed detailed notes of all participant contact, including number of calls made, call attempts, time spent on each call, topics addressed, stage of change, and call outcome. Participants' indication of a receipt of a DFE was documented for later validation by chart audit. The outcome of the telephone conversation was coded using 12 categories developed for this research study, including: 1) Bad time/Call back; 2) Not willing to talk about VIP, diabetes or eyes; 3) No interest in making an appointment at this time; 4) Thinking about making an appointment; 5) Verbal commitment to make an appointment; 6) Appointment completed; 7) Appointment missed or cancelled; 8) Appointment kept, DFE completed; 9) Thinking about rescheduling a missed appointment; 10) Verbal commitment to reschedule appointment; 11) Appointment rescheduled; 12) Tried to make an appointment, but could not. These twelve codes are important as they highlight the potential number of process steps required to follow through on this screening recommendation. Finally, the content of the call was coded using the following categories: 1) rapport building, 2) health education, 3) logistical support, 4) problem solving and 5) all other content.

Participants completed a pre-intervention survey and a post-intervention survey six months after randomization into the print or telephone intervention group. This survey assessed self report of receipt of a DFE, confirmed later by a medical chart audit. The main outcome for the study was a documented receipt of a DFE within the 6-month window. Trained staff, masked to group assignment, performed on-site medical chart reviews to verify DFE by either an ophthalmologist or qualified optometrist. One person was responsible for traveling to the health centers to perform chart audits on receipt of DFE; she was not an interventionist for this study.

Data Analysis Plan

Statistical analyses were carried out using Stata version 9.1. Exploratory analyses focused on examining the factors that contribute to receiving a DFE within 6 months for participants in the tailored telephone intervention using Pearson chi-square and logistic regression analysis. Logistic regression was used to estimate models with the DFE outcome as the dependent variable, and demographic background factors (language, ethnicity, gender, race), outcome codes, and ethnicity of interventionist as predictors.

Results

A qualitative analysis was completed of participants' pre-intervention survey responses to the open-ended question: "When you think of diabetes complications, what is the first complication that comes to your mind?". The most frequent response was "eye problems," reported by 19% of the 206 respondents to that item, even though at the time of the survey participants were unaware that this study was focused on improving retinopathy screening rates. The second most frequent response was "foot problems" reported by about 17% of participants, followed by cardiovascular-related issues reported by 12%.

Demographics and Receipt of DFE at 6 Months

Table 2 displays the demographic background characteristics for telephone intervention participants. The majority of the telephone intervention group was English-speaking (76.4%), Black (45.9%), non-Hispanic (53.1%) and female (60.7%). The average age in the intervention group was 56.4 (SD = 12.6) years; the average duration since the diagnosis of diabetes was 8.9 years (SD = 7.2). There were no significant differences between randomized groups for these characteristics.

The relationship between age, ethnicity, race, sex, language, and the number of telephone calls completed by those in the telephone intervention was assessed using the Mann-Whitney, Kruskal-Wallis equality of populations rank test, and t-test for independent samples. Results revealed that there was no relationship between the demographic background characteristics and number of calls completed.

Demographics by DFE Outcome Group

Data was examined with Pearson chi square to determine if there were any differences by background variables (gender, ethnicity, race and language) for those in the telephone intervention who received a DFE as compared to those in the telephone intervention who did not receive a DFE (see Table 3). The analysis revealed no significant differences by background variable.

Number of Calls and Receipt of DFE at 6 Months

Participants could receive up to 7 calls over a 6-month period. Telephone intervention participants received on average 3.5 calls (SD = 1.7) and spoke with a health educator for an average of 31.4 minutes total (SD = 26.7) over the course of the intervention. There were 930 completed telephone calls to the telephone group participants, lasting 8.8 minutes on average per call. A sensitivity analysis showed that nearly all participants who obtained a DFE did so after 4 or fewer phone calls; all did so by the fifth phone call. There was no gain by doing a sixth or seventh phone call.¹⁹

Outcome Codes and Receipt of DFE at 6 Months

Data were examined with Pearson chi square to determine if there were any differences in outcome codes for those in the telephone intervention who received a DFE as compared to those in the telephone intervention who did not receive a DFE. The analysis revealed that the distribution of participants receiving each outcome code differed significantly by DFE

outcome group, $\chi^2(13, N = 292) = 58.82, p < .01$. Participants in telephone intervention who did not receive a DFE had significantly more outcome codes (presumably more steps in the behavioral process) than those who received a DFE; however there was no significance at the univariate level (see Table 4).

Ethnic Concordance by DFE Outcome Group and Health Educator

Data was examined with Pearson chi square to determine if there were any differences by ethnic concordance of participant and health educator for those in the telephone intervention who received a DFE as compared to those who did not receive a DFE. Here ethnic concordance refers to whether the participant and health educator shared the same ethnic background (Hispanic vs. non-Hispanic). The analysis revealed that ethnic concordance was not significantly associated with success in receiving a DFE, $\chi^2(1, N = 299) = 1.29, p = .25$ (see Table 5).

Content Codes and Receipt of DFE at 6 Months

The effects of proportion of total time devoted to a particular content theme on DFE outcome were explored using a multivariate logistic regression. Results are presented in Table 6. The goodness of fit for this model was reasonable (Hosmer-Lemeshow test, $p = .28$) and the overall model was significant ($p < .0004$). The coefficients for rapport building and health education were significant. More specifically, there was a negative association between the time spent rapport building and receipt of DFE. As time spent engaging in health education activities by phone increased, the likelihood of receiving a DFE increased. Time spent in logistical rapport was marginally significant.

Risk Perception Survey and Receipt of a DFE

An important finding regarding worry related to complications of diabetes as measured in the Risk Perception Survey was reported in the main results paper for VIP.¹³ For those in the telephone intervention who had a higher baseline level of worry regarding complications, there was an odds ratio of 3.47 (95% CI=1.78–6.77) for having a dilated eye exam within the intervention 6 months; this was not true for those with higher worry in the print intervention.¹³

Discussion

A modest telephonic intervention based on behavioral theory and delivered by health educators under the supervision of a certified diabetes educator increased the rate of screening for diabetic retinopathy by 74% in a disadvantaged urban population. This paper describes the telephonic intervention and variables associated with receipt of a retinopathy screening by a DFE.

There are several significant findings worth noting. This intervention had multi-ethnic success and appeal, as there were no significant differences by demographic characteristics for those who did or did not receive a DFE. Participants who did not receive a DFE had significantly more outcome codes (i.e., steps in their behavioral process) than those who received a DFE (see Table 4). This could be reflecting the difference between early adoption

of a behavior compared to later adoption, including greater number of phone calls with more intervening steps.

We also examined the impact of interventionist and participant ethnic background concordance. The analysis revealed that ethnic concordance was not significantly associated with DFE outcome group (see Table 5). Some contend that ethnic and racial concordance is important for delivery of healthcare interventions,²⁰ while others suggest that racial and ethnic concordance is not an important factor. The findings from our analysis suggest that ethnic concordance did not play a role in receipt of DFE for those in the telephone intervention. This finding may be because the intervention was limited to only seven phone calls over six months, as opposed to a long-term health counseling in-person relationship. The fact that a single behavior was the focus of the intervention may also explain this unexpected finding.

The results also suggest that time spent building rapport and time spent in health education were significant variables for receipt of DFE (see Table 6). More specifically, there was a negative association between the time spent in general rapport building and receipt of DFE. It is important for health educators to spend time building rapport with participants, but spending more time building general rapport was associated with a decrease in receipt in DFE. This is logical, as time spent on general rapport building decreases the amount of time spent talking to a participant about health-related issues such as prevention of diabetes retinopathy. It may also reflect a participant who was not ready to discuss retinopathy screening. On the other hand, time spent engaging in patient education increased the likelihood of receiving a DFE.

Finally, the evidence that the a higher level of baseline worry about diabetes complications, in conjunction with a tailored intervention including problem-solving and health education, was significantly more successful than worry and a print intervention for promoting retinopathy screening. A level of worry can be motivating for behavior change when combined with the telephonic self-management support in VIP.

Implications and Recommendations

These results demonstrate the successes, challenges, and lessons learned from conducting a tailored telephone intervention focused on a single self-management behavior of screening to prevent eye complications. Health educators from diverse ethnic and racial backgrounds trained and supervised by a nurse CDE can successfully deliver this intervention. Those designing health interventions should be aware that while rapport building is important to reach out and connect to a participant, targeted health education is necessary to change the behavior. As described in our published report of the costs of the intervention for a minority, low-income population¹⁹, we suggest that this telephonic intervention implemented by health educators for diabetes patients could be considerably less expensive than in our main study (over \$300 per dilated eye exam completed) if it were imbedded in a health care setting which included an efficient appointment system for referrals to specialists, such as ophthalmologists. The description of this intervention should be useful to those developing

interventions targeted to improve retinopathy screening rates in community and health care settings for diverse urban populations.

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Table 1**Examples of Intervention Talking Points**

Assess knowledge: Can you tell me what you've heard/know about eye problems related to diabetes?

- One complication of diabetes is diabetic retinopathy. It can cause bleeding in the back of your eyes making it difficult to see. It can lead to blindness if not treated.
- Often times there are no symptoms of eye disease. You may have eye disease and not even know it.
- The only way to know if you have eye disease is to be checked for it by having a dilated eye exam once a year.
- If eye disease is found, there are very effective ways to treat the problem early and save your eyesight.

Dialog: Have you ever had a dilated eye (DE) exam?

If Yes: When did you go last? What was it like? Are you thinking/willing to go for another DE exam? What has stopped you from getting another DE exam?

If No: Has your doctor ever told you to go for a DE exam? Can you tell me why you haven't gone for a DE exam? Have you tried to make an appointment for a DE exam? What's stopping you from making an appointment or going for a DE exam? What needs to happen in order for you to go for a DE exam?

Dialog: Are you ready to make an appointment and go for a dilated eye exam?

If Yes: Do you have the phone number to make an appointment? How will you remember to go for your appointment? How will you get there? How confident are you that you can go for this exam? What will help you make your decision to go for this exam? I'd like to call you again to see how it was for you to make your appointment. Is that okay? How much time will you need? When would you like me to call again?

If No: Can you tell me why you are not interested in making an appointment at this time? What are the things/barriers today that keep you from making an appointment? What will help you make an appointment in the future? Can I call you in a few weeks to speak about this again? I'd like to call you back after you've had some time to think about what we've talked about today. I can answer any questions and go over other information with you again. How about if I call you back in 2 weeks? Is that okay?

Table 2

Demographic Background Characteristics for Telephone Intervention Participants (N=305)

Variable	N	%
Language of interview		
English	233	76.4
Spanish	72	23.6
Total	305	100
Race		
Black	140	45.9
White	50	16.4
Asian	9	3.0
> one race	23	7.5
Refused	1	.33
Don't know	8	2.6
Unknown	74	24.4
Total	305	100
Ethnicity		
Hispanic	124	40.7
Non-Hispanic	162	53.1
unknown	19	6.2
Total	305	100
Sex		
Male	120	39.3
Female	185	60.7
Total	305	100

Table 3
 Comparison of Dilated Fundus Exam (DFE) Outcome by Demographics: Pearson Chi-Square (N = 305)

Variable	No DFE	DFE	Total	χ^2	<i>p</i>
Language				.23	.63
English	156	77	233		
Spanish	46	26	72		
Race				9.53	.14
Black	97	43	140		
White	37	13	50		
Asian	4	5	9		
> one race	17	6	23		
Don't know	4	4	8		
Unknown	43	31	74		
Ethnicity				.81	.66
Hispanic	79	45	124		
Non-Hispanic	111	51	162		
unknown	12	7	19		
Gender				.13	.71
male	78	42	120		
female	124	61	185		

Table 4

Frequency of Telephone Outcome Code by Dilated Fundus Exam (DFE) Outcome Group

Outcome Code	No DFE	DFE	Total
Bad time/call back	1	1	2
Not willing to about VIP, diabetes or eyes	4	0	4
No interest in making an appointment at this time	14	3	17
Thinking about making an appointment	36	16	52
Verbal commitment to make an appointment,	52	23	75
Appointment completed	12	32	44
Appointment missed or cancelled	6	0	6
Appointment kept, DFE completed	37	9	46
Thinking about rescheduling appointment	1	1	2
Verbal commitment to reschedule appointment	6	1	7
Appointment rescheduled	6	4	10
Tried to make an appointment but could not.	1	0	1
Other	9	0	9
Missing data	17	0	17
Total	202	90	292

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Table 5

Chi Square Analysis of Ethnic Concordance by Dilated Fundus Exam (DFE) Outcome Group

Ethnic Concordance	No DFE	DFE	Total
Unmatched Ethnicity	114	52	166
Matched Ethnicity	83	50	133
Total	197	102	299

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Table 6

Multivariate Logistic Regression Coefficients for Proportions of Total Time Spent on Particular Content Themes as Predictors of Dilated Fundus Exam (DFE) Outcome

Variable	Coefficient	<i>p</i>
Proportion of Time Spent on:		
Rapport Building	-.39	.00
Health Education	2.6	.02
Logistics	3.8	.06
Problem Solving	-12.6	.27

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