COMPLIANCE WITH RECOMMENDATIONS FOR FOLLOW-UP CARE IN LATINOS: THE LOS ANGELES LATINO EYE STUDY

Miguel Unzueta, MD; Denise Globe, PhD; Joanne Wu, MS; Sylvia Paz, MS; Stanley Azen, PhD; Rohit Varma, MD, MPH; and the *Los Angeles Latino Eye Study Group

Purpose: To determine rates of follow-up eye and health care in the Los Angeles Latino Eye Study (LALES), a population-based sample of Latinos.

Methods: Participants received a complete ophthalmic examination and were referred to a local healthcare provider for follow-up care, if ocular or systemic disease was found. Participants receiving referrals were later contacted by telephone and interviewed in their language of choice (English or Spanish) by a trained bilingual interviewer, to determine follow-up rates, and to discuss the barriers preventing follow-up care.

Results: Of 430 referred participants, 335 (78%) completed the follow-up survey; 278 (68%) of the responders obtained follow-up care. Among the 108 (32%) individuals who did not seek follow-up care, 54 (50%) cited cost of care as the main reason, while 30 (28%) indicated a lack of knowledge as to where to go for care, and 18 (17%) indicated the unavailability of health care. Logistic regression analyses (controlling for acculturation, co-morbid conditions, and patients' prior knowledge of their diagnoses) revealed that participants with insurance coverage, diagnosis with a systemic disease, and higher educational level were more likely to have received follow-up care.

Conclusion: More than two thirds of the participants reported seeking the recommended follow-up care. Although cost, availability of services, and convenience of accessing care were found to be major barriers to obtaining health care, higher education, insurance coverage, and prior knowledge of the disease, were associated with receiving recommended care. Knowledge of barriers to seeking health care is important when developing community based healthcare programs directed toward the Latino population. (*Ethn Dis.* 2004;14: 285–291.)

Key Words: Epidemiology, Latinos, Self-Reported Follow-Up

Department of Ophthalmology, Keck School of Medicine (MU, SP, SA, RV), Department of Pharmaceutical Economics and Policy, School of Pharmacy (DG, JW), Department of Preventive Medicine, Keck School of Medicine (SA, RV), University of Southern California, Los Angeles, California. *See Appendix I for the members of the Los Angeles Latino Eye Study.

INTRODUCTION

The United States Census Bureau projects that by 2010 an additional 31 million Latinos will reside in the United States, bringing the total Latino population to 281 million. During the next 2 decades, Latinos will account for one of every 3 new additions to the United States population.[1] Of interest is the scarcity of information about Latino health-seeking behaviors. This is problematic, since Latinos are at higher risk for developing diabetes and hypertension, 2 co-morbid conditions that can lead to loss of sight.[2] The San Antonio Heart Study has reported that Mexican Americans are 2 to 5 times more likely than Whites to develop type 2 diabetes,[1,3–5] a major public health concern, since diabetes is the leading cause of visual impairment and blindness among Americans aged 20 to 74 years.[6] In fact, individuals with diabetes are 25 to 30 times more likely to go blind than are persons without diabetes of similar age and gender.[7] In addition, an estimated 60% to 65% of persons with diabetes have high blood pressure, another co-morbid condition that can accelerate the loss of vision.[8,9]

Current population-based ocular epidemiological studies, such as the Baltimore Eye Study, and the Beaver Dam Eye Study, primarily focus on the number of people screened, the related demographic data, and the amount of po-

tential disease detected among Whites and African Americans.[10,11] Although these studies provide insight into the prevalence and incidence of ocular disease, they do not address receipt of care by those who have been identified as having disease. This information is crucial, because it can provide the clinician with insight into factors that may influence whether a patient will obtain the recommended care.

The health-seeking behaviors of many Latinos, especially the elderly, may be associated with acculturation, as well as sociodemographic factors. Current literature on the significance of acculturation describes methods of measuring acculturation and the proportion of Latinos who are acculturated. Some studies hypothesize that the level of acculturation is associated with access to care; however, this association has yet to be established.[12] Other studies describing sociodemographic factors report that the use of mammography for breast cancer screening in Latinos is associated with being younger, and having a source of medical care.[13] Findings from the Hispanic Health and Nutrition Survey suggest that factors facilitating access to care among Latinos are more strongly related to the use of preventive services, than to acculturation, after controlling for differences in patient demographics, such as age, income, and education.[14] Additionally, social support has been identified as a factor that facilitates preventive care.[15–17] However, these studies fail to address patterns of, and barriers to, seeking health care, specifically in Latino patients after the presence of a disease has been identified.[18]

The purpose of this study was to: 1) estimate the proportion of participants

Address correspondence and reprint requests to Rohit Varma MD, MPH; Doheny Eye Institute; 1450 San Pablo St., Suite 4900; Los Angeles, CA 90033-1088; 323-442-6411; 323-442-6412 (fax); rvarma@usc.edu

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who sought follow-up ocular or health care after being advised to do so by a physician at an ocular examination center; 2) identify the sociodemographic characteristics of individuals who did not obtain follow-up care; 3) describe the barriers that prevented some participants from receiving recommended follow-up ocular or systemic health care; and 4) provide insight into sociodemographic and clinical factors that may facilitate the use of health care in the Latino Community.

METHODS

Baseline Assessment

The Los Angeles Latino Eye Study (LALES) is a population-based prevalence survey of ocular disease in non-institutionalized, self-identified Latinos, aged 40 years and older, in 6 adjacent census tracts in and around the city of La Puente, California. The Institutional Review Board of the University of Southern California approved the study protocol. All study procedures adhered to the Declaration of Helsinki for research involving human subjects. After informed consent was obtained, sociodemographic information (usual source of care, acculturation level, and insurance status) and clinical characteristics (self-reported history of ocular and medical disease) were collected through an in-home interview. A subsequent detailed medical examination and a complete ocular examination were completed in the LALES clinic.

The cohort for this study consisted of 430 self-identified Latinos, who were diagnosed with either ocular or systemic disease during a clinical examination by an ophthalmologist. These participants were recommended to obtain follow-up care within one month of the examination. Participants who reported having a usual source of care were referred to their own physician. Participants with insurance coverage and no usual source of care were given a list of providers to choose from. Those without insurance or a usual source of care were referred to the nearest county healthcare facility.

Approximately 3 months after the participants were referred for care, a trained bilingual interviewer contacted each participant to administer a follow-up survey. Five attempts were made to contact each participant by telephone at various times of the day and week. If they were not successfully contacted after 5 phone attempts and 3 home visits, participants were considered non-responders.

Follow-Up Assessment

A short computer-based follow-up survey was used to identify: 1) whether the participants obtained recommended follow-up care; and 2) factors which precluded or facilitated follow-up care (eg, social support and barriers to healthcare access). The survey was administered via telephone in either English or Spanish, according to each responder's preference. This survey, which took approximately 8 minutes to complete, consisted of 3 primary sections: 1) a clinic follow-up section, which introduced the participant to the purpose of the telephone survey, allowed the interviewer to determine the participant's referral status, and established the skip logic protocol for the remainder of the survey; 2) a general barriers section, asked only of those who did not receive follow-up care, which consisted of 9 questions derived from the Hispanic Health and Nutrition Survey,[14] and the

Medical Expenditure Panel Survey,[19] to assess the participant's perceived barriers to follow-up care; and 3) a Social Support section asked of all responders, which consisted of three questions adapted from Murray and McMillan,[19] and was designed to examine the participants' perceived social support. The social support questions documented the participants' perception of the emotional support from the family, financial support from the family, and perceived burden on the family caused by his/her illness.

Classification of Participants

Participants were classified as either "Responders" (individuals who could be contacted by telephone or in person) and "Non-responders" (individuals who could not be contacted at all). Responders were further classified as "Follow-up responders" (those who obtained recommended follow-up care) and "Non-follow-up responders" (those who did not obtain recommended follow-up care).

Demographic and Clinical Characteristics

Demographic and participant characteristics that were thought to be associated with receipt of care were obtained from both the baseline and follow-up interviews. Based on previous studies, having fewer barriers to receiving care, perceiving greater social support, having a usual source of care, and exhibiting higher acculturation scores, were expected to be associated with receipt of recommended follow-up care.[14–17] Acculturation, a process of culture learning and behavioral adaptation, takes place when individuals are exposed to a new culture, and was measured using the short Cueller Acculturation scale developed for the Hispanic Health and Nutrition Survey.[14,20,21] Scale scores range from 1 to 5, with 5 representing the highest level of acculturation. Whether the participant had a usual source of care prior to the LALES ex-

Table 1. Socio-demographic and clinical characteristics stratified by response status

Characteristics	Responders (N=335)	Non-responders (N=95)	P value*
Socio-Demographic Characteristics			
Age in years	58.1 (11.1)	60.0 (11.6)	.21
Female	195 (58%)	52 (55%)	.55
High school graduate	101 (30%)	21 (22%)	.39
Employed	121 (36%)	30 (32%)	.67
Married	222 (66%)	61 (64%)	.74
Annual household income <$20,000	153 (46%)	49 (52%)	.08
Acculturation†	1.8 (0.9)	1.7 (0.8)	.20
Usual source of care	249 (74%)	64 (67%)	.18
Clinical Characteristics			
Self-reported number of comorbidities‡	1.5 (1.4)	1.6 (1.4)	.44
Prior diagnosed disease§			.89
Ocular disease	220 (60%)	58 (61%)	
Systemic disease	133 (39.7%)	37 (39%)	
Prior knowledge of diagnosis	132 (39%)	43 (45%)	.03
Prior treatment	89 (26%)	31 (33%)	.43
Use glasses for near vision	145 (43%)	36 (38%)	.35

Note: sample sizes vary slightly for some variables because of missing data (eg, 57 participants refused/not know their income).

* Categorical variables reported as frequency (%); continuous variables reported as mean (SD). Chi-square test for categorical variables; Student *t* test for continuous variables.

† Acculturation scale score's range is from one to 5, 5 representing the highest acculturation.

‡ Self-reported comorbidities: diabetes, high blood pressure, arthritis, stroke, angina, heart attack, heart failure, asthma, skin cancer, other cancer, back problems, deafness/hearing problems.

§ Ocular diseases included cataract, glaucoma, diabetic retinopathy, and age-related macular degeneration. Systemic diseases included diabetes, and hypertension.

amination was evaluated by a self-reported item ("Is there a particular clinic, health center, doctor's office, or other place that you usually go to if you are sick or need advice about your health, or for routine care?").

Based on previous research[22] age, gender, marital status, income, education, and employment status, were included as covariates in the analyses. It was important to determine whether receipt of follow-up care was initiated by the interaction with the physician at the LALES clinic, or was a continuation of behaviors that existed prior to participation in the study. Two variables were created from the database to determine whether the participant knew of the diagnosis (cataract, glaucoma, age-related macular degeneration, diabetes, or hypertension) prior to the examination, and whether treatment had been received for the condition prior to the study. These variables were created by comparing the ICD-9 code for the par-

ticipants' diagnoses and their self-reported ocular and systemic disease histories, along with their treatment history.

Since the number of co-morbid conditions has been demonstrated to be an important factor in the use of healthcare services[23,24] we included a Co-morbidity Summation Score,[25] computed as a summation of items from a list of 12 self-reported, non-ocular-related medical conditions, including diabetes, high blood pressure, arthritis, stroke, angina, heart attack, heart failure, asthma, skin cancer, other cancer, back problems, and deafness/hearing problems.

Statistical Analysis

Descriptive statistics were used to estimate the distribution of sociodemographic and clinical characteristics, as well as the proportion of participants who received follow-up care. The characteristics were then compared between the responders and non-responders to

assess the impact of non-participants on the results. Next, factors that facilitated or impeded (barriers) the receipt of follow-up care were compared between follow-up responders and non-follow-up responders, using chi-square tests for categorical variables, and *t* tests for continuous variables.

Finally, univariate and stepwise forward logistic regression analyses were used to identify characteristics that facilitated receipt of follow-up care. Factors shown to be associated with seeking health care in univariate analyses at the P<.25 level were candidates for the stepwise analyses. Independent variables associated with the receipt of follow-up care after the ophthalmic examination included education level, disease type (ocular or systemic disease), having health or vision insurance, income level, number of co-morbidities, having a usual source of care, having prior knowledge of diagnosis, and receiving prior treatment. All statistical tests were conducted at the P=.05 level using SAS software (SAS Institute, Cary, NC).

RESULTS

Demographic and Clinical Characteristics

Of the 4,498 LALES participants who were examined for systemic and ocular disease, 430 (9.6%) were referred for further care. Two hundred sixty participants (60%) were referred for eye care, and 170 (40%) were referred for general (systemic) health care. Three hundred thirty-five (78%) of the participants completed a follow up survey (responders) and 95 (22%) did not complete the follow-up survey (non-responders) for the following reasons: 51 (54%) could not be reached after 5 telephone attempts and 3 home visits, 37 (39%) had moved, 3 (3%) refused further participation in the study, and 4 (4%) had died.

As shown in Table 1, responders were similar to non-responders with re-

spect to age, gender, education level, employment status, marital status, income level, acculturation, number of co-morbidities, diagnosed systemic or ocular disease, and the prevalence of prior treatment, and the use of glasses for near vision (*P*>.05). Additionally, there was no difference between the 2 groups with respect to having a usual source of health care. However, prior knowledge of the LALES study diagnosis was significantly greater for non-responders, as compared to responders (*P*=.03).

Self-Reported Receipt of Follow-up Care

Of the 335 participants who completed a follow-up survey, 227 (68%) obtained follow-up care, and 108 (32%) did not. Table 2 summarizes the socio-demographic, health services, insurance status, clinical, and social support characteristics of follow-up responders and non-follow-up responders. Follow-up responders were similar to non-follow-up responders with respect to gender, employment status, marital status, and income (*P*>0.05). In contrast, non-follow-up responders were an average of 3.2 years younger (*P*<0.01) than follow-up responders. They also were less educated (*P*<.001), less acculturated (*P*<.01), less likely to have a usual source of care (*P*<.01), and less likely to have medical (*P*<.0001) and vision (*P*<.001) insurance. Additionally, non-follow-up responders had fewer co-morbid conditions (*P*<.05), were less likely to have diagnosed systemic disease (*P*<.0001), were less likely to know their diagnosis prior to the LALES clinic examination (*P*<.01), were less likely to be under treatment prior to the LALES clinic examination (*P*<.04), and were less likely to use glasses for near vision (*P*<.001).

The majority of follow-up responders reported having some form of social support. Seventy-nine percent had emotional support, and 54% had financial support; however, 51% felt they would be a burden to their family if they de-

Table 2. Socio-demographic, clinical, and social support characteristics stratified by follow-up status in responders

Demographic and Clinical Characteristics	Follow-up Responders (*N*=227)	Non-follow-up Responders (*N*=108)	*P* value*
Socio-Demographic Characteristics			
Age in years†	59.1 (11.3)	55.9 (10.3)	<.01
Female	129 (57%)	66 (61%)	.46
High school graduate	83 (37%)	18 (17%)	<.001
Employed	81 (36%)	40 (37%)	.81
Married	146 (64%)	76 (70%)	.26
Income <$20,000	97 (43%)	56 (52%)	.16
Acculturation‡	1.9 (1.0)	1.6 (0.8)	<.01
Has usual source of care	180 (79%)	69 (64%)	<.01
Has medical insurance	172 (76%)	54 (50%)	<.0001
Has vision insurance	132 (58%)	41 (38%)	<.001
Clinical Characteristics			
Number of comorbidities§	1.6 (1.4)	1.2 (1.3)	<.005
Prior diagnosed disease‖			<.0001
Ocular disease	118 (52%)	84 (78%)	
Systemic disease	109 (48%)	24 (22%)	
Knew of diagnosis prior to the study	103 (45%)	29 (27%)	<.01
Received treatment prior to the study	68 (30%)	21 (19%)	.04
Use glasses for near vision	112 (49%)	33 (31%)	.001
Social Support¶			
Emotional support	174 (79%)	86 (83%)	.41
Financial support	110 (54%)	47 (48%)	.40
Burden to family	100 (51%)	52 (58%)	.23

Note: Sample sizes vary slightly for some variables because of missing data (eg, 40 participants refused/did not know their income and one non-follow-up responder's ICD-9 was not available).

Percentages may not add up exactly to 100 due to rounding error (eg, follow-up responders' education levels).

* Categorical variables reported as frequency (%); continuous variables reported as mean (SD). Chi-square test for categorical variables; Student *t* test for continuous variables.

† Mean (SD).

‡ Acculturation scale score's range is from one to 5, 5 representing highest acculturation.

§ Self-reported comorbidities: diabetes, high blood pressure, arthritis, stroke, angina, heart attack, heart failure, asthma, skin cancer, other cancer, back problems, deafness/hearing problems.

‖ Ocular diseases included cataract, glaucoma, and age-related macular degeneration. Systemic diseases included diabetes, and hypertension.

¶ There were 10 missing values for emotional support, 33 for economic support, and 49 for burden to family.

Table 3. Barriers to obtaining follow-up care in responders who did not obtain follow-up care (*N*=108)

Barriers to Obtaining Follow-up	N (%)
Cost	54 (50%)
Did not know where to go	30 (28%)
Care not available	18 (17%)
No transportation	12 (11%)
Long clinic waiting time	11 (10%)
No Spanish-speaking eye doctor	7 (6%)
Thought problem was not serious	6 (6%)
Could not understand doctor	4 (4%)
Doctor did not care	3 (3%)

veloped medical problems. Among those responders who perceived having social support, there was no significant difference between follow-up responders and non-follow-up responders (Table 2).

Self-Reported Barriers

Table 3 summarizes the self-reported barriers for those who did not obtain follow-up care (non-follow-up responders). The primary reasons for not obtaining follow-up care were cost (50%), and lack of information about where to obtain care (28%). Thirty-four percent of those who did not obtain follow-up

Table 4. Stepwise logistic regression of factors predicting follow-up care

Factor/ Characteristic	Included Responders		Odds Ratio Estimates OR (95% CI)	*P* value
	Follow-up (*N*=227)	Non-follow-up (*N*=108)		
Diagnosed disease*				<.0001
Ocular diseases	118 (52%)	84 (78%)	1.0	
Systemic diseases	109 (48%)	24 (22%)	3.4 (2.0, 5.9)	
Education				.001
<12 years	144 (63%)	90 (83%)	1.0	
≥12 years	83 (37%)	18 (17%)	2.7 (1.5, 5.0)	
Health insurance				<.0001
No	54 (24%)	54 (50%)	1.0	
Yes	172 (76%)	54 (50%)	2.9 (1.8, 5.0)	

* Ocular diseases included cataract, glaucoma, and age-related macular degeneration. Systemic diseases included diabetes and hypertension.

care did not report experiencing any of the barriers to receiving health care.

Factors Associated with Follow-Up Care

Stepwise logistic regression analysis (Table 4) revealed that a diagnosis of systemic disease, being more educated (>12 years), and having health insurance, were significantly associated with obtaining follow-up care (all *P*<.05). Factors not included in the model were employment (employed compared to unemployed), income level (household income above or below $20,000), having a usual source of care, number of co-morbidities, having prior knowledge of the condition, or receiving prior treatment for this condition.

DISCUSSION

Study Findings

Among non-hospitalized Latinos in Los Angeles who had received a recommendation for a follow-up examination, 68% reported having received follow-up care. Factors associated with seeking care were: having health insurance, diagnosis with a systemic disease, and educational level, after adjusting for other demographic and participant characteristics. Most of the participants who failed to seek care cited cost and

not knowing where to go as the main reasons for this. This study assessed follow-up care in Latinos with strikingly high self-reported follow-up rates, and is unique in several ways. First, it assessed compliance with physician-recommended follow-up care, rather than care-seeking behavior initiated by the participant. Second, it assessed receipt of care in a Latino population. Third, it assessed the association between receipt of care and factors that have been hypothesized to be important in determining healthcare-seeking behaviors in the Latino population.

Most of the health services literature has assessed the use of care, and reported factors that facilitated or impeded care-seeking for initial diagnosis in primarily Caucasian populations. Reported barriers to receipt of initial care have included transportation, time, cost, lack of emotional and social support, and a history of negative experiences with the healthcare system, particularly for Latinos.[26] In this study, the primary reasons for not obtaining follow-up care recommended by the physician (cost and not knowing where to obtain care) were similar to reasons previously reported. Interestingly, of the 32% of participants who did not obtain recommended follow-up care, more than one third did not perceive a barrier to receipt of care. This suggests that other factors may play

a role in compliance with treatment recommendations.

One study conducted among male Hispanics employed by a public work site in Arizona examined the factors that contributed to the delayed use of medical care when chronic disease-related symptoms occurred. A model describing the factors underlying receipt of health care was developed using focus groups and a survey of employees. It was found that the seriousness of symptoms had the greatest effect on healthcare-seeking behavior, with more serious conditions leading the individuals to seek care sooner.[26] This is similar to the results from Quigley et al,[27] who found that participants with more serious or involved medical conditions were likely to obtain follow-up care. Furthermore, it was found that faith in God, and the seriousness of symptoms, were both related to an increase in the search for a doctor one could trust (cultural construct of *confianza*). In our study, participants with systemic disease were more likely to obtain follow-up care than those with ocular disease. One explanation might be a lack of knowledge of, or belief in, the seriousness of ocular disease. Perhaps the participants were more familiar with the serious impact on health and function associated with hypertension and diabetes, than with that of ocular diseases such as glaucoma, diabetic retinopathy, cataract, and age-related macular degeneration.

More than two thirds of the participants who received a recommendation for follow-up care obtained it within 3 months of their LALES clinical examination. This, at first, appears to be in contrast to current literature, which suggests that chronic disease prevention and control interventions designed for the general US population have not been effective in reaching Latinos, or changing behaviors in the use of care.[26,28] Previous research has shown that Latinos who are less acculturated, and of lower socioeconomic status, believe less in the value of early detection,

and are more fatalistic and less likely to seek preventive health care.[29,30] However, our findings are actually consistent with previous findings. Individuals who had not received care prior to the clinical examination were less likely to seek care after the examination. Those with lower income and less education were also less likely to receive care. Therefore, our findings support those of previous studies that suggest the current methods for disease prevention and control programs are not effective in encouraging appropriate use of the healthcare system for a segment of the Latino population.

Recommendations for Provision of Care to Latinos

Several salient features of the LALES clinic make it Latino-friendly, which may have increased the likelihood of a participant complying with recommended follow-up care. Protocols and training of the LALES staff incorporated the important cultural concepts including *confianza*[26] (trust) and *respeto* (respect) to maximize participation and satisfaction. First, all LALES clinic personnel, including the ophthalmologist, speak Spanish, and either were from the community, or were raised in a Latino environment. Thoroughly informing the participants about the study and assuring them of the authenticity of the research, as well as emphasizing that their participation would "indirectly help their children," enhanced *confianza* in the project. Clinicians also enhanced *respeto* by addressing the patients as señor, señorita, and señora, which is an important show of respect. The time spent examining, explaining, and conversing with the participant was another integral component in displaying the values of *confianza* and *respeto*.

One potential limitation of this study was that the participants were of predominantly Mexican-American heritage, therefore potentially limiting the applicability of the results to the larger Latino population, which includes Puerto Ricans, Dominicans, and Cuban

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Americans. However, the results of this study are generalizable to an important segment of the Latino population, since Mexican Americans are the largest growing segment of the Latino community, as well as the most under-served in terms of healthcare delivery.[31–37] Mexican Americans are more likely to seek care later in the course of disease, which can result in significant morbidity and mortality. This results in the potential loss of years of life, as well as potentially higher treatment costs. Another limitation is the use of self-reported data to determine rates of follow-up care and co-morbid medical conditions. Self-reported utilization has been shown to correlate well with medical records across varying ethnic groups,[38] although a small degree of under-reporting of physician visits may occur.[39] In one study, elderly patients demonstrated almost perfect agreement on self-reported measures of whether or not a contact occurred, but poorer agreement on the number of visits.[40,41] Similarly self-reported co-morbidities have been shown to be accurate across a number of conditions, as well as among different ethnic groups.[42,43]

Further clarification of the interaction between cultural belief systems, provision of health care, and patient health-seeking behaviors, will be an important focus for future research. This

information will directly affect efficient and effective physician management of Latino patients with ocular disease.

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AUTHOR CONTRIBUTIONS

Design and concept of study: Unzueta, Globe, Azen, Paz, Varma
Acquisition of data: Unzueta, Globe, Wu, Azen, Paz, Varma
Data analysis and interpretation: Unzueta, Globe, Wu, Azen, Paz, Varma
Manuscript draft: Unzueta, Globe, Wu, Azen, Paz, Varma
Statistical expertise: Globe, Wu, Azen, Paz, Varma
Acquisition of funding: Unzueta, Azen, Varma
Administrative, technical, or material assistance: Paz, Varma
Supervision: Globe, Paz, Varma

APPENDIX I

The Los Angeles Latino Eye Study Group

Study Site: University of Southern California, Los Angeles, California. Rohit Varma, MD, MPH (Principal Investigator); Sylvia H. Paz, MS (Project Director); LaVina Abbott; Stanley P. Azen, PhD (Co-Principal Investigator); Lupe Cisneros, COA; Elizabeth Corona; Carolina Cuestas, OD; Denise R. Globe, PhD; Sora Hahn, MD; Mei Lai, MS; George Martinez; Susan Preston-Martin, PhD; Ronald E. Smith, MD; Mina Torres, MS; Natalia Uribe, OD; Joanne Wu, MPH; Myrna Zuniga

Battelle Survey Research Center, St. Louis, Missouri. Sonia Chico, BS; Lisa John, MSW; Michael Preciado, BA; Karen Tucker, MA

Ocular Epidemiology Grading Center, University of Wisconsin, Madison, Wisconsin. Ronald Klein, MD, MPH