# Barriers to Follow-Up and Strategies to Improve Adherence to Appointments for Care of Chronic Eye Diseases

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**Purpose.** To understand factors associated with poor attendance of follow-up appointments for care of glaucoma (GL), AMD, and diabetic retinopathy (DR) in a tertiary referral center, and to identify strategies to improve adherence.

**Methods.** Cross-sectional study of 240 adults attending follow-up appointments for GL, AMD, or DR. Cases ($N = 102$) were patients with poor follow-up who missed and failed to reschedule an appointment within 1 month of the recommended follow-up date during the preceding year. Controls ($N = 138$) were patients who completed the assigned follow-up. Data regarding the factors impacting adherence to appointments were collected via an orally administered questionnaire. Multivariate logistic regression was performed to determine factors associated with poor follow-up.

**Results.** In a multivariate logistic regression model, independent factors significantly associated with poor follow-up included incorrectly answering more than 50% of questions about eye disease (adjusted odds ratio [OR] = 3.24, $P = 0.001$), legal blindness (adjusted OR 2.64, $P = 0.013$), the presence of glaucomatous versus retinal disease (adjusted OR 2.06, $P = 0.013$), and difficulty for the study subject and/or escort taking time away from work for the appointments (adjusted OR 1.80, $P = 0.049$). Subjects identified the following strategies to improve follow-up: contact with others having the same eye condition (41.3%), greater education regarding eye disease (40.8%), and improved transportation services to the clinic (44.6%).

**Conclusions.** Low disease knowledge scores, legal blindness, and difficulty getting time away from work for appointments adversely impacted follow-up independent of eye disease diagnosis. Improvements in patient education, transportation services, and clinic efficiency may increase adherence to recommended appointment intervals.

Keywords: glaucoma, age-related macular degeneration, diabetic retinopathy, follow-up, appointment adherence

Age-related macular degeneration (AMD), diabetic retinopathy (DR), and glaucoma (GL) are chronic degenerative diseases that require regular follow-up appointments to optimally monitor a patient's course and adjust therapy.[1–5] Common patient- and system-level factors impeding timely follow-up, such as advanced age, distance from clinic, and transportation, have been documented across an array of medical and surgical disciplines.[6–9] Several recent articles have revealed that patients with chronic eye diseases are struggling to adhere to scheduled appointments.[10–20] Some have suggested that because chronic vision loss and disease progression are often subtle, patients may be less motivated to have timely follow-up due to a perception that their eye disease is not serious.[10,12–14,21–25] It is critical to understand the reasons why patients miss recommended appointments because lack of monitoring or treatment may lead to poor outcomes, including blindness.[11]

Recent studies have combined medical record data with self-administered questionnaires or patient interviews to uncover reasons for inconsistent eye care follow-up.[10,12–14,22,26] Hispanic and Indian diabetics have been shown to lack awareness of screening guidelines for retinopathy.[12–14] Among GL patients in India, a questionnaire-driven study found that minimal or no formal education, noncompliance with glaucoma eye drops, and the perception that follow-up is less important if they are compliant with their medication regimen, significantly predicted poor glaucoma follow-up.[21] Others have shown that lower education level and being Latino/African American predicted inconsistent follow-up among GL patients in a county hospital.[22]

While these papers have described the barriers to follow-up in indigent, county hospital populations and India, our aim was to describe the barriers associated with poor follow-up for a patient population in a suburban tertiary care facility, where socioeconomic factors like low education, limited finances, and lack of awareness of one's eye condition may be less prevalent. To increase the generalizability of our study, we interviewed patients with any of three chronic eye diseases: GL, DR, or AMD.

We hypothesized that misperceptions about one's eye disease or the importance of follow-up, good visual acuity, and poor knowledge base would not be associated with poor follow-up in our population. Our study demonstrates that independent of the type of chronic eye disease, a significant association exists between poor follow-up and legal blindness, low disease knowledge scores, and difficulty for the study subject and/or escort to take time away from work for the appointment.

## Methods

We conducted a cross-sectional study of 240 individuals attending follow-up ophthalmology appointments at an academic suburban eye clinic during the period between June 1 and November 30, 2009. Human subject approval was obtained from the institutional review board at the affiliated academic institution. The project adhered to the tenets of the Declaration of Helsinki. We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during this research. Eligibility criteria included age greater than 18 years and a medical record that documented treatment at the clinic for a diagnosis of GL, AMD, or DR for at least 12 months. Individuals were excluded if they were a new referral or had more than one of the aforementioned diseases.

### Recruitment

Upon arrival for their eye appointment, eligible subjects were invited for a private oral interview by one of two trained study investigators. Interpreters were used to interview 22 patients who were not fluent in English. Of the 260 individuals eligible for the study, 7.7% (20) declined to participate due to time constraints. A total of 102 cases agreed to participate in the study. One hundred thirty-eight controls were enrolled to adequately power the study to detect an odds ratio (OR) of 2.0 or greater with an alpha of 0.05 and beta of 0.20 for a power of 80% to detect a significant difference between cases and controls in predictors of poor follow-up if such a difference existed. The study was not powered to detect differences in barriers to follow-up between retinal eye diseases. Both informed consent and study questionnaires were administered orally in order to include patients whose poor vision limited their ability to read. Patients did not receive compensation for their voluntary participation in the study.

### Operational Definition of Poor Follow-up

Because the time frame for follow-up was individualized based on disease severity and treatment regimen, subjects were categorized as cases of poor follow-up if at any time in the 12 months preceding their oral interview, they had failed to reschedule a missed or patient-cancelled appointment within 1 month of the desired follow-up date despite receiving a call from the clinic. This criteria was set a priori so that findings would be comparable to prior studies.[21]

### Measures

Data were collected from patient interviews and chart review using a questionnaire on barriers to follow-up, strategies to improve follow-up, disease knowledge, and perceptions that may impact follow-up patterns. This questionnaire had been developed in India,[21] and validated through a 14-patient pilot study for use in the United States.[22,26] Most questions only required replacement of the term 'GL' with 'AMD' or 'DR' for use with retinal patients. Disease knowledge questions 1 and 2, and questions about treatments required disease-specific content substitutions and were piloted on five AMD or DR patients before the study (Supplementary Table S1 and Questionnaire).

### Sociodemographic and Medical Characteristics

Demographic and clinical information including age, sex, race/ethnicity, English fluency, primary language, educational level, employment, health insurance, evaluation at an outside clinic, procedure history, eye surgery history (Table 1), eye disease diagnosis, visual acuity, and travel time to clinic (Table 2) were collected from the medical record and verified in the interview. Patients estimated the number of years since eye disease diagnosis and self-reported compliance and cost burden of eye-related medications. Intraocular pressure (IOP) was not available for most retinal patients, so this data could not be collected. Snellen visual acuity was converted into logMAR units for the purposes of statistical analysis. Non-Snellen acuities were converted to logMAR units in a manner used in a prior study: counting fingers = 1.6, hand motions = 1.9, light perception = 2.2, no light perception = 2.5 based upon recommendation.[27] Categorical variables were also created to compare patients who were or were not legally blind, and to compare those with 20/20 to 20/25 visual acuity in both eyes to those with worse than 20/25 visual acuity. Likert scales were used to rate the convenience of transportation, difficulty coming to appointments, and perceived safety.

### Disease Knowledge and Sources of Information

Patients selected the resources they had used to learn about their eye disease (i.e., ophthalmologists/clinic staff, pamphlets/posters, family/relatives/friends, media-TV/radio/internet, primary care physician). They answered five questions that assessed their knowledge base about their eye disease pathogenesis and follow-up treatment. Disease knowledge scores were calculated as the percentage of questions answered incorrectly (e.g., number of questions answered "no" or "not sure" divided by total number of questions; Supplementary Table S1).

### Patient Perceptions About Disease Severity and Follow-up

Patients used a Likert scale to grade their perception of their eye disease severity, their difficulty attending appointments, whether they believe attending follow-up appointments is important, and whether they think they should attend appointments if they do not notice any change in their vision despite treatment.

### Barriers to Follow-up

Patients answered "Yes" or "No" as to whether predefined items (i.e., long wait times, etc.) had been a significant barrier to attending follow-up exams in the past year (Supplementary Questionnaire). For the purpose of analysis, items with a similar theme were grouped into general categories (Table 3). For example, if a patient reported that either clinic visit fees, transportation costs, or lost wages had been a significant barrier to their follow-up attendance, they were categorized as having a "financial barrier" to follow-up. Items with too few responses to analyze are not reported.

### Strategies to Improve Follow-up

Patients were asked to answer "Yes" or "No" as to whether any items on a list of potential strategies would help them attend their follow-up appointments (Supplementary Questionnaire).

### Statistical Analyses

Statistical analysis was completed using STATA (12.1; College Station, TX, USA), R (x64 2.14.1; Vienna, Austria), and R studio

**Table 1.** Bivariate Analysis of Demographic Factors Associated With Adherence to Follow-up Appointments

| | Follow-up *N* (%) | | Unadjusted OR for Poor Follow-Up (95% CI) | *P* Value* |
|---|---|---|---|---|
| | Poor 102 (42.5) | Good 138 (57.5) | | |
| Age, mean (SD) | 70.5 (14.3) | 72.2 (14.7) | NA | 0.37 |
| Sex | | | | |
| Male | 47 (46.1) | 63 (45.7) | 1.02 (0.61–1.7) | 1 |
| Female | 55 (53.9) | 75 (54.3) | 1 (Reference) | NA |
| Race/ethnicity | | | | |
| Nonwhite | 46 (45.1) | 46 (33.3) | 1.64 (0.97–2.78) | 0.065 |
| Asian | 31 (30.4) | 26 (18.8) | 1.96 (1.06–3.66) | 0.03 |
| Latino | 5 (4.9) | 14 (10.1) | 0.59 (0.18–1.63) | 0.33 |
| Black | 5 (4.9) | 3 (2.2) | 2.74 (0.65–13.8) | 0.26 |
| Other | 5 (4.9) | 3 (2.2) | 2.74 (0.65–13.8) | 0.26 |
| White | 56 (54.9) | 92 (66.7) | 1 (Reference) | NA |
| English fluency | | | | |
| No | 13 (12.7) | 9 (6.5) | 2.1 (0.87–5.27) | 0.10 |
| Yes | 89 (87.3) | 129 (93.5) | 1 (Reference) | NA |
| Primary language | | | | |
| Not English | 42 (41.2) | 43 (31.2) | 1.55 (0.91–2.64) | 0.11 |
| Asian dialect | 26 (25.5) | 19 (13.8) | 2.17 (1.11–4.30) | 0.02 |
| Spanish | 3 (2.9) | 13 (9.4) | 0.37 (0.08–1.19) | 0.13 |
| Other | 13 (12.7) | 11 (8.0) | 1.87 (0.79–4.52) | 0.16 |
| English | 60 (58.8) | 95 (68.8) | 1 (Reference) | NA |
| Educational level | | | | |
| High school or less | 24 (23.5) | 32 (23.2) | 1.02 (0.55–1.86) | 0.95 |
| College/Graduate Degree | 78 (76.5) | 106 (76.8) | 1 (Reference) | NA |
| Employment† | | | | |
| Working | 18 (17.65) | 33 (23.9) | 0.68 (0.35–1.28) | 0.24 |
| Not working | 84 (82.25) | 105 (76.1) | 1 (Reference) | NA |
| Health insurance | | | | |
| Subsidized (Medi-Cal, Medicare, etc.) | 34 (33.3) | 33 (23.9) | 1.59 (0.90–2.82) | 0.11 |
| Unsubsidized (private) | 68 (66.7) | 105 (76.1) | 1 (Reference) | NA |
| Seen at outside facility in the past year | | | | |
| Yes | 21 (20.6) | 40 (29.0) | 0.64 (0.34–1.15) | 0.14 |
| No | 81 (79.4) | 98 (71.0) | 1 (Reference) | NA |
| Clinic procedure history | | | | |
| Laser | 2 (1.96) | 5 (3.6) | 0.52 (0.57–3.41) | 0.47 |
| Intravitreal injection | 27 (26.5) | 61 (44.2) | 0.58 (0.22–1.47) | 0.25 |
| Visual fields | 63 (61.8) | 59 (42.8) | 1.39 (0.57–3.41) | 0.47 |
| No procedure | 10 (9.8) | 13 (9.4) | 1 (Reference) | NA |
| History of eye surgery | | | | |
| Yes | 69 (67.6) | 86 (62.3) | 1.26 (0.74–2.17) | 0.39 |
| No | 33 (32.4) | 52 (37.7) | 1 (Reference) | NA |

* *P* values were calculated using the Wald test in unadjusted logistic regression models except for difference in mean age, which was calculated using a *t*-test.

† Not working: retired, unemployed. Working: at least part-time.

(0.96.228). Mean age was compared using a *t*-test, but duration of eye disease was compared using a Wilcoxon rank-sum test because it was not normally distributed. Proportions for categorical variables were compared using Pearson $\chi^2$ or Fisher's exact test where appropriate. Unadjusted logistic regression models were fit with individual demographic, clinical, or self-reported characteristics as the independent variables and follow-up status as the dependent variable. Multivariate logistic regression analysis was then performed for the final analysis. Seven independent variables that had reached *P* less than 0.05 in the unadjusted bivariate analysis were entered into a multivariate model and successively eliminated based upon failure to demonstrate statistical significance ($P < 0.05$). Adjusted ORs and 95% confidence intervals (CIs) were calculated for the final multivariate logistic regression model.

## Results

Of the 240 subjects enrolled in the study, 121 were diagnosed with GL, 86 with AMD, and 33 with DR. The proportion of poor follow-up cases defined as those who had failed to

**Table 2.** Bivariate Analysis of Clinical or Self-Reported Factors Associated With Follow-up

| | Follow-Up *N* (%) | | Unadjusted OR for Poor Follow-Up (95% CI) | *P* Value* |
|---|---|---|---|---|
| | Poor 102 (42.5) | Good 138 (57.5) | | |
| Disease category | | | | |
| Glaucoma | 63 (61.8) | 58 (42.0) | 2.23 (1.33–3.78) | 0.003 |
| Retinal eye disease | 39 (38.2) | 80 (57.9) | 1 (Reference) | NA |
| AMD | 29 (28.4) | 57 (41.3) | 1.17 (0.50–2.87) | 0.72 |
| DR | 10 (9.8) | 23 (16.7) | 1 (Reference) | NA |
| Duration of eye disease, y | | | | |
| Median (Range) | 6 (1–50) | 6 (1–55) | NA | 0.34‡ |
| Visual acuity CC† | | | | |
| Legally blind | 13 (13.4) | 4 (2.9) | 5.1 (1.74–18.6) | 0.006 |
| Not legally blind | 84 (86.6) | 132 (97.1) | 1 (Reference) | NA |
| 20/20–20/25 | 16 (16.5) | 18 (13.2) | 1.29 (0.6–2.7) | 0.49 |
| Not 20/20 | 81 (83.5) | 118 (86.7) | 1 (Reference) | NA |
| Missing Data | 5 (4.9) | 2 (1.4) | NA | NA |
| Failure to attend an appointment without cancellation | | | | |
| Yes | 44 (43.1) | 34 (24.6) | 2.32 (1.34–4.05) | 0.003 |
| No | 58 (56.9) | 104 (75.4) | 1 (Reference) | NA |
| Missed appointments, % | | | | |
| Greater than 25% | 62 (60.1) | 54 (39.1) | 2.41 (1.43–4.1) | 0.001 |
| 25% or less | 40 (39.2) | 84 (60.9) | 1 (Reference) | NA |
| Incorrect answers on disease knowledge, % | | | | |
| Greater than 50% | 27 (26.5) | 17 (12.3) | 2.56 (1.32–5.10) | 0.006 |
| 50% or less | 75 (73.5) | 121 (87.7) | 1 (Reference) | NA |
| Travel time | | | | |
| 60 min or greater | 27 (26.5) | 28 (20.3) | 1.41 (0.77–2.92) | 0.26 |
| Less than 60 min | 75 (73.5) | 110 (79.7) | 1 (Reference) | NA |
| Mode of transportation | | | | |
| Not Car | 11 (10.7) | 20 (14.5) | 0.71 (0.32–1.56) | 0.40 |
| Bus | 1 (0.98) | 6 (4.3) | 0.22 (0.02–1.82) | 0.16 |
| Walking | 3 (2.9) | 3 (2.2) | 1.29 (0.25–6.57) | 0.75 |
| Bicycle or motorcycle | 3 (2.9) | 0 (0) | NA | NA |
| Transportation service | 4 (3.9) | 11 (8.0) | 0.47 (0.15–1.53) | 0.21 |
| Car | 91 (89.2) | 118 (85.5) | 1 (Reference) | NA |
| Transportation§ | | | | |
| Inconvenient | 68 (66.7) | 75 (54.3) | 1.68 (0.99–2.87) | 0.055 |
| Convenient | 34 (33.3) | 63 (45.7) | 1 (Reference) | NA |
| Difficulty for patient/escort to take time away from work or home§ | | | | |
| Difficult | 69 (67.7) | 74 (53.6) | 1.81 (1.07–3.1) | 0.029 |
| Easy | 33 (32.3) | 64 (46.4) | 1 (Reference) | NA |
| Physical difficulty coming to clinic‖ | | | | |
| Difficult | 23 (33.6) | 18 (13.0) | 1.94 (0.98–3.83) | 0.056 |
| Easy | 79 (77.4) | 120 (85.5) | 1 (Reference) | NA |
| Perceived difficulty in attending follow-up appointments‖ | | | | |
| Difficult | 71 (69.6) | 81 (58.7) | 1.61 (0.94–2.79) | 0.084 |
| Easy | 31 (30.4) | 57 (41.3) | 1 (Reference) | NA |
| Perception of disease severity | | | | |
| Mild | 40 (39.2) | 45 (32.6) | 1.33 (0.78–2.28) | 0.29 |
| Moderate/severe | 62 (60.8) | 93 (67.4) | 1 (Reference) | NA |

* *P* values were calculated using the Wald test in unadjusted logistic regression models.

† Visual acuity measured in both eyes with correction. Total number of patients less than 240 due to seven patients with missing data when patient's corrected visual acuity was not recorded in the patient chart. *P* value includes control for missing data, which attenuated the response.

‡ *P* value from Wilcoxon rank-sum test.

§ Inconvenient expressed as somewhat or very inconvenient. Convenient expressed as convenient or not inconvenient.

‖ Difficulty expressed as somewhat or very difficult. Easy expressed as easy or not too difficult.

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**Table 3.** Bivariate Analysis of Self-Reported Barriers to Attending Follow-Up Appointments in the Past Year

| | Follow-Up *N* (%) | | | |
|---|---|---|---|---|
| | **Poor 102 (42.5)** | **Good 138 (57.5)** | **Unadjusted OR for Poor Follow-Up (95% CI)** | ***P* Value*** |
| Long wait times | | | | |
| Yes | 53 (52.0) | 51 (37.0) | 1.85 (1.1–3.1) | 0.021 |
| No | 49 (48.0) | 87 (63.0) | 1 (Reference) | NA |
| Difficulty rescheduling† | | | | |
| Yes | 38 (37.3) | 37 (26.8) | 1.62 (0.93–2.81) | 0.085 |
| No | 64 (62.8) | 101 (73.2) | 1 (Reference) | NA |
| Financial barriers‡ | | | | |
| Yes | 26 (25.5) | 21 (15.2) | 1.91 (1.004–3.66) | 0.049 |
| No | 76 (74.5) | 117 (84.8) | 1 (Reference) | NA |
| Work responsibilities | | | | |
| Yes | 12 (11.8) | 9 (6.5) | 1.91 (0.78–4.9) | 0.16 |
| No | 90 (88.2) | 129 (93.4) | 1 (Reference) | NA |
| Other medical/physical illness | | | | |
| Yes | 24 (23.5) | 25 (19.6) | 1.39 (0.74–2.6) | 0.30 |
| No | 78 (76.5) | 113 (81.9) | 1 (Reference) | NA |
| Lack of an escort | | | | |
| Yes | 22 (21.6) | 27 (19.6) | 1.13 (0.60–2.12) | 0.70 |
| No | 80 (78.4) | 111 (80.4) | 1 (Reference) | NA |

* *P* values were calculated using the Wald test in unadjusted logistic regression models.

† Cancellations by the clinic, rescheduling difficulty, and difficulty rescheduling 6 months in advance were not individually statistically significant.

‡ Clinic fees, transportation costs, and lost wages were not individually statistically significant.

reschedule a missed appointment within 1 month of the desired follow-up date, was 52.1% (63/121), 33.7% (29/86), and 30.3% (10/33) for those with GL, AMD, and DR, respectively. The glaucoma diagnosis, which included primary and secondary open angle, angle closure, and other categories, did not significantly impact whether patients had poor follow-up ($P = 0.649$); similarly, there were no differences in follow-up among those with exudative versus nonexudative AMD, or proliferative versus nonproliferative DR ($P = 0.722$). The 20 patients who declined to participate in the study did not differ from the 240 study subjects with regard to follow-up status, eye disease diagnosis, sex, age, or visual acuity measures ($P > 0.05$, all comparisons).

Bivariate analysis of participant demographic information is presented in Table 1. A majority of study subjects were White ($n = 148$, 61.6%), retired ($n = 189$, 78.8%), privately insured ($n = 173$, 72.1%), and college-educated ($n = 184$, 76.7%). The most common mode of transportation to clinic was by car ($n = 209$, 87.0%), whether driven by the patient or an escort, while a smaller proportion of patients used transportation services for the visually impaired ($n = 15$, 6.3%). There were no statistically significant differences in follow-up by race, fluency in English, or insurance. Asian ethnicity (OR 1.96, $P = 0.03$) and Asian dialect as a primary language (OR 2.17, $P = 0.02$) were significantly associated with poor follow-up; this finding was attenuated when controlling for financial barriers (OR 1.7, $P = 0.1$ and OR 1.97, $P = 0.053$, respectively). Intravitreal injections were only reported by patients with retinal eye disease ($n = 13$ [39.9%] DR, $n = 75$ [87.2%] AMD, $n = 0$ [0%] GL). Those who received intravitreal injections were less likely to have poor follow-up (OR = 0.45, 95% CI 0.26–0.79, $P = 0.005$) than those who did not. This difference did not remain statistically significant after controlling for retinal disease subtype (AMD versus DR; $P = 0.26$). Self-reported missed dose(s) of topical glaucoma medications during the week preceding study enrollment did not significantly correlate with poor follow-up (OR 1.48, $P = 0.42$).

Table 2 shows the bivariate analysis for factors potentially associated with poor follow-up. Glaucoma diagnosis was significantly associated with poor follow-up relative to AMD and DR ($P = 0.009$ and $P = 0.029$, respectively). The study was not powered to detect the small difference in follow-up (OR 1.17) between the two retinal disease groups ($P = 0.72$), which were grouped together in the final multivariate analysis. A one-unit increase in visual acuity on the logMAR scale in either eye was not significantly associated with worse follow-up (OR = 1, $P > 0.89$) or with type of eye disease (OR = 1, $P > 0.24$). Legal blindness, however, was significantly associated with poor follow-up ($P = 0.006$).

Table 3 shows a bivariate analysis of information provided by subjects with regard to barriers to follow-up. The most frequently reported barrier was a long wait time ($n = 104$, 43.3%) followed by rescheduling difficulties ($n = 75$, 31.25%). Self-reported long waiting times (OR 1.85, $P = 0.02$) and financial barriers (OR 1.91, $P = 0.049$) were also significantly associated with poor follow-up in this bivariate analysis but not in the final multivariate model. Self-reported medical or physical illness and lack of an escort were prevalent self-reported barriers, but were not significantly associated with poor follow-up ($P = 0.30$, $P = 0.70$, respectively) (Table 3). Overall, 97.9% ($n = 235$) of subjects reported believing that follow-up was very important, and 95.8% (181/189) persisted in this belief even if they did not notice any treatment benefit in terms of visual health.

A multivariate logistic regression model (Table 4) was constructed using the seven characteristics that reached statistical significance in bivariate analysis ($P < 0.05$). Financial barriers, self-reported long clinic waits, and Asian race/ethnicity were eliminated because they failed to show statistical significance in the multivariate model. Only four independent predictors reached a statistical significance level

Table 4. Independent Predictors of Poor Adherence to Follow-Up Appointments after Multivariate Logistic Regression Analysis

| | OR for Poor Follow-up (95% CI) | | |
|---|---|---|---|
| | Unadjusted | Adjusted | Adjusted *P* Value* |
| Final multivariate model† | | | |
| Glaucoma vs. retinal eye disease | 2.23 (1.33–3.78) | 2.06 (1.16–3.64) | 0.013 |
| Difficult for patient/escort to take time away from work/home | 1.81 (1.07–3.1) | 1.80 (1.01–3.22) | 0.049 |
| Legal blindness in both eyes | 5.1 (1.7–18.6) | 2.64 (1.22–5.71) | 0.013 |
| Incorrect answers to >50% of disease knowledge questions | 2.56 (1.32–5.10) | 3.24 (1.58–6.69) | 0.001 |

* *P* values were calculated using the Wald test in multivariate logistic regression.
† Final multivariate model retained covariates with *P* values $< 0.05$.

of *P* less than 0.05 sufficient to be retained in the final multivariate model: a diagnosis of glaucoma as opposed to retinal eye disease, incorrectly answering more than 50% of questions regarding disease pathogenesis and treatment, being legally blind, and patient or escort difficulty in taking time away from home or work for appointments ($P < 0.05$ for all comparisons).

Table 5 shows patient sources of information about their eye disease and strategies patients believed would help to improve follow-up.

## Discussion

Our results demonstrate that even in a predominantly nonindigent suburban clinic population, challenges to follow-up remain highly prevalent among patients with chronic eye diseases. These findings complement prior work performed in the developing world as well as among indigent and county hospital populations in developed world urban settings.[12–14,17,21–22,26] Several factors were associated with poor follow-up, independent of whether one had glaucomatous or retinal eye disease including, having less understanding of the mechanism and trajectory of one's eye disease, patient or escort difficulty getting time off work for appointments, and legal blindness. While confirmatory research is lacking, one can hypothesize that poor follow-up and the possible resultant delay in appropriate care may contribute to unnecessary progression of eye disease, particularly in circumstances where effective therapy is available to those who may be getting worse.

Table 5. Patient-Reported Sources of Information About One's Eye Disease and Potential Strategies to Improve Attendance of Follow-Up Appointments

| | Total *N* (%) 240 (100) |
|---|---|
| Patient Sources of Eye Disease Information | |
| Ophthalmologists and staff at the clinic | 202 (84.2) |
| Pamphlets and posters | 131 (54.6) |
| Family, relatives, and friends | 93 (38.8) |
| Media-TV, radio, internet | 118 (49.2) |
| Primary care physician | 48 (20) |
| Potential strategies to improve follow-up | |
| Preappointment reminder (by phone, text, or email) | 196 (81.7) |
| Parking vouchers | 115 (47.9) |
| Transportation service to and from the clinic | 107 (44.6) |
| Mobile eyecare van | 77 (32.1) |
| Networking with other patients with the same eye disease | 99 (41.3) |
| More education on one's eye disease | 98 (40.8) |
| More education on the importance of follow-up | 72 (30.0) |

Previous studies have suggested that patients with less advanced disease[11] or those who think their disease is not severe are less adherent to scheduled follow-up appointments.[10,21,22] We, however, did not find that poor follow-up correlated with either milder visual impairment or a perception that one's eye disease was not severe. In contrast to the results reported by Lee et al.[21] and Murakami et al.[22] subjects in our study denied that they failed to attend appointments because they did not believe that the disease posed a threat to their vision. Nearly all patients in our study sample, regardless of disease type, expressed a belief that follow-up was important, even if they did not notice a change in their vision with medication or other treatment, and perception that one's eye disease was mild was not significantly associated with worse follow-up in our study sample ($P = 0.29$). We also found that patients with good visual acuity (20/20–20/25) were not more likely to have poor follow-up relative to those with worse than 20/25 visual acuity ($P = 0.49$). Visual acuity on a logMAR scale likewise did not significantly differ based upon follow-up status or whether one had retinal versus glaucomatous disease ($P > 0.20$). The difference in our findings most likely reflects the difference in our sampling frame, which drew from a primarily nonindigent suburban clinic population rather than indigent populations in county hospitals or developing nations.

We found that legal blindness correlated with poor follow-up in our study population independent of whether one had glaucoma or a retinal eye disease. It is possible that blind patients may be poorly motivated to attend future appointments if there is little vision to be salvaged. An alternate explanation for the findings is that those who follow-up less regularly are more likely to experience disease progression to blindness. Because greater disease severity increases the probability of noticeable vision loss and, in some cases, blindness, it is not surprising that Ung et al.[17] found that more severe glaucoma correlates with worse follow-up. It has also been previously demonstrated that those with very poor vision are more likely to rely on an escort to get them to a clinic setting, a factor known to limit compliance with follow-up appointments.[21,28] We similarly found that difficulty receiving time off from work for the patient or their escort was associated with poor follow-up,[28] independent of disease type.

Although nearly all study subjects stated that they were aware that follow-up was important, incorrectly answering more than 50% of questions about their eye disease was significantly predictive of poor follow-up, independent of whether they had glaucoma or a retinal disease. This finding was unexpected given that our population consisted mostly of college-educated, English-speaking subjects. A majority of study subjects learned about their eye disease primarily from the ophthalmology staff at the clinic, yet only a handful reported that the clinic had provided them with resources or a support network to help them manage their eye condition.

Only 20% of patients learned about their eye disease from their primary care physician and such contact did not correlate with better follow-up, a finding that has previously been found among Hispanic diabetics.[12] Such data draw attention to the fact that challenges in the management of chronic eye diseases may stem from uncoordinated or insufficient efforts in patient education and support by healthcare staff.

In the multivariate model, there was a residual association of glaucoma disease type with poor follow-up independent of the other factors in the model. This association is not explained by visual acuity or self-reported perception of eye disease, which were not associated with follow-up or disease type. Rather, any number of unmeasured confounders may explain why glaucoma patients were less likely to follow-up. For example, it is possible that patients who undergo invasive therapeutic procedures at clinic may be subconsciously more motivated to keep appointments than those who do not. Clinic visits for the treatment of retinal diseases more often include concomitant laser therapy and intravitreal injections, whereas glaucoma patients are managed primarily through efforts to lower IOP with eye-drops, and less commonly with laser treatments or surgery. In our study, only retinal patients reported receiving intravitreal injections and these injections were significantly associated with better follow-up. This association did not remain significant if one controlled for the type of retinal eye disease (AMD versus DR) but it may have been limited by cohort size.

### Limitations

One limitation of our study was the modest sample size, which limited the power to evaluate differences that may exist between retinal eye diseases (i.e., AMD versus DR). Though inclusion of multiple chronic eye diseases increased generalizability, this is a single-institution study of limited socioeconomic or ethnic diversity. Nevertheless, we did find that patients of Asian ethnicity or who speak an Asian dialect, and those with financial constraints, were less likely to follow-up. Asians and patients with limited English proficiency have been shown to have delays in treatment of other chronic diseases such as epilepsy,[29,30] and long wait times for interpreters have been documented among glaucoma patients of Asian ethnicity in a county setting.[26] Our finding was partially attenuated by controlling for financial constraints. Larger studies are needed to examine the degree to which access to language-appropriate care may adversely impact follow-up among Asians with chronic eye diseases.

As with other interview-based studies, there may be selection bias if those who declined participation were influenced by their follow-up history or other factors that impact follow-up. Less than 10% of individuals declined to participate and this group did not differ from those enrolled with regard to demographic characteristics. Oral in-clinic interviews have the potential to introduce bias compared with other methods (e.g., telephone interviews, mail-in questionnaires) if patients feel pressured to provide socially acceptable answers or are concerned that their responses may be disclosed to their providers despite assurances by the investigators. We attempted to minimize this bias by assuring patients of the anonymity of their responses and conducting their interviews in private. Patients were free to discontinue the interview at any time, though no patient elected to do so. The study may underestimate the true prevalence of poor follow-up because it does not capture data on patients entirely lost to follow-up. Alternatively, the 1-month cut-off for rescheduling may overestimate poor follow-up, especially if applied when there is inclement weather. However, patients who met this definition of poor follow-up were more than twice as likely to have failed to attend an appointment without cancelling and to have missed more than 25% of their appointments in the preceding year (Table 2), which suggests that this criteria does capture patients with inconsistent follow-up patterns. Given the study design, establishment of a baseline visual acuity was also not feasible and temporal associations could not be assessed. Future studies should collect longitudinal data and employ alternative techniques such as mailed questionnaires or phone interviews to capture data about patients who stop attending eye appointments altogether.

## Conclusions

Our study shows that even in a population of insured and educated patients, nonadherence with scheduled follow-up appointments is prevalent. Significant barriers to making appointments independent of disease type included difficulty getting time off to attend appointments, incomplete understanding of the pathogenesis and treatment of one's eye disease, and legal blindness. Patients reported that interventions to improve education and clinic efficiency and to increase networking opportunities among patients with chronic eye conditions could help improve their compliance with follow-up. Creation of affordable transportation for those who rely on escorts due to poor vision may also have a positive impact. Recent trials in chronic disease management have shown that remote support interventions through telephone, email, and websites can provide substantial benefits to patients similar to those achieved by in-person counselors and coaches.[31,32] Assessment of the influence of such interventions on adherence to follow-up should be the focus of future studies.

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