THE UTILIZATION OF EYE CARE SERVICES BY PERSONS WITH GLAUCOMA IN RURAL SOUTH INDIA

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ABSTRACT

Purpose: To determine utilization of eye care services, in particular those relating to glaucoma, in a rural population of southern India aged 40 years or older.

Methods: A total of 5,150 subjects aged 40 years or older selected through a random cluster sampling technique from three districts in southern India underwent detailed ocular examinations for vision impairment, blindness, and ocular morbidity. Information regarding previous use of eye care services was collected from this population through a questionnaire administered by trained social workers prior to ocular examinations.

Results: One thousand eight hundred and twenty-seven persons (35.5%) gave a history of prior eye examinations, primarily from a general hospital (n = 1,073, 58.7%). Increasing age and education were associated with increased utilization of eye care services. Among the 3,323 persons who had never sought eye care, 912 (27.4%) had felt the need to have an eye examination but did not do so. Only one third of persons with vision impairment, cataracts, refractive errors, and glaucoma had previously utilized services. Of the 64 subjects diagnosed as having primary open-angle glaucoma, 32 (50%) had previously seen an ophthalmologist, but none had had an eye examination within 1 year before the study. Only six (19%) of the 32 had been diagnosed as having glaucoma (9% of all subjects found to have glaucoma in the survey). Thirteen (20.3%) of the 64 subjects were blind in either eye due to glaucoma, including one person who was bilaterally blind.

Conclusions: A large proportion of persons in a rural population of southern India who require eye care are currently not utilizing existing eye care services. Strategies to improve the uptake of services are required to reduce the burden of blindness due to glaucoma in southern India.


INTRODUCTION

Glaucoma is a major cause of global blindness. Regional and racial differences in the prevalence of glaucoma have been reported, with significant variations in visual loss that may apparently differ by ethnic group. India has over 1 billion people and has a huge burden of visual impairment and blindness. Studies have reported the prevalence of glaucoma from urban and rural populations in south India. In these populations, age-related cataract was the leading cause of bilateral blindness in those over 40 years of age. This accounts for 77.5% of bilateral blindness. Glaucoma was responsible for 10.2% and optic atrophy for 8.2% of bilateral blindness.

Various measures have been employed in an attempt to reduce the burden of blindness in the United States. For preventable blindness to be minimized, persons must first utilize the available eye care resources. Preslan and Novak found poor utilization of already existing resources in the pediatric age group. Following a primary school screening, when financial and transportation barriers were removed and free eyeglasses were provided, only 30% of children wore glasses and 80% failed the school screening 1 year later. Quigley and coworkers evaluated the utilization of eye care following screening.
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held at churches and community centers during daytime, evenings, and weekends. They found that even in this ideal situation, where transportation was paid for, visits were free, and locations were convenient, only 17% of all who were asked to schedule a definitive examination did so. Only 60% diagnosed as having definite ocular pathology returned for follow-up. Seventeen subjects had been previously diagnosed as having glaucoma, prior to the study; and 24% of them had been lost to follow-up for at least a year. In the 27 subjects diagnosed as having glaucoma, 5 (29%) were lost to follow-up. In the group with suspected glaucoma, 3 of 7 (43%) who were told they needed drops actually returned. Likewise, 25 of 37 (68%) who were told they did not need drops, but were suspected of having glaucoma, were lost to follow-up.

The low level of utilization of eye care has been previously documented in prevalence surveys in developed nations. The Baltimore Eye Survey found that within a five-mile radius of the Wilmer Institute (Johns Hopkins Hospital), 35.8% of people older than 45 years were needlessly disabled by curable cataracts, 6.6% by diabetic retinopathy, and 4.7% by glaucoma.19 Had these individuals utilized available eye care, much of this disability might not be present.

The utilization of eye care is less than ideal in more developed nations. Little is known about the utilization of available eye care resources for glaucoma in less developed nations. Blindness is a major public health care problem in India despite relatively recent sustained efforts by the ophthalmic community that has seen a doubling of cataract surgical output to 3.5 million in 2000. However, we have found that more than 40% of those with bilateral blindness had never visited an eye doctor.20 Previous studies have reported on the barriers to eye care services in south India and have found that economic reasons and access to care (including transportation and lack of persons to accompany patients) were among the most important reasons that persons blind with cataract did not seek care.21,22 The ophthalmic community can address some of these identified barriers. However, a large proportion of individuals who have preventable visual disability require focused and sustained interventions, including, but not limited to, improving literacy, improving health education, and improving practical aspects of access to health care, such as transportation.

The high rates of blindness prevailing in India despite the sustained improved efforts of the ophthalmic community suggest that a larger national and community-based concerted effort is required to reduce blindness in India to manageable levels. Besides improving infrastructure and manpower, a major challenge will be to address the barriers currently preventing a large proportion of the blind population from utilizing existing services.

We have noted that almost three quarters of those older than 40 years had poor vision necessitating eye care, yet only 61% of those needing eye care services had ever previously sought such services.28 Diseases such as glaucoma can be treated if detected early enough, and the risk of visual disability or loss can be significantly minimized.28-30 There are many reasons for blindness due to primary open-angle glaucoma (POAG). These include, but are not limited to, inability to screen and diagnose glaucoma, inadequate or inaccurate therapy, lack of compliance, and nonutilization of available facilities.

To the best of our knowledge, there have been no previous reports on utilization of eye care services by persons with glaucoma in less developed nations. This study reports on the utilization of eye care services by subjects with glaucoma identified through a population-based survey in rural south India.

METHODS

The design and methodology of the Aravind Comprehensive Eye Survey (ACES) have been previously published.16 Briefly, ACES is a population-based cross-sectional survey carried out between November 1995 and February 1997 among rural residents aged 40 years or older in three districts of southern India (Madurai, Tirunelveli, and Tuticorin) to assess the burden of ocular morbidity and blindness (Figure 1). The sampling frame for this study consisted of a sample of typical rural areas (equivalent to counties within the United States) that are served by the Aravind eye hospitals that are located in both Madurai and Tirunelveli districts, India. During the period of the study, these hospitals provided free eye care to over 50% of all patients (Figure 2) and gave free surgical care to over 60% of all patients (Figure 3).

![Map of India showing the locations of Aravind Eye Hospitals](https://example.com/figure1.png)

**FIGURE 1** Locations served by the Aravind eye care hospitals where the Aravind Comprehensive Eye Survey was carried out.
Subjects for the study were identified through a stratified systematic random cluster sampling technique. The sampling frame for this study consisted of a sample of typical rural districts in order to best reflect the rural population in the southern part of India. This sample is representative of rural areas in south India, but not necessarily of urban areas there or of rural or urban areas further north in India.

Comprehensive ocular examinations were offered to all subjects aged 40 and older who resided in selected geographic areas and were willing to be part of the study. Comprehensive ocular examinations were performed at the base hospital and included slit-lamp biomicroscopy, lens grading using the Lens Opacities Classification System III (LOCS III), applanation tonometry, gonioscopy, visual fields using automated perimetry, and dilated fundus examinations with indirect ophthalmoscopy and 90-diopter lens for all subjects. Visual acuity was measured with retroilluminated ETDRS charts, and refraction was performed for all subjects. Examiners were standardized for the study prior to the start of the study and at regular intervals during the study period.

Intraocular pressure (IOP) was measured using Goldmann applanation tonometry at the slit lamp with the patient under local anesthesia. Three consecutive measurements were taken and recorded, and the median measurement was considered as the IOP for analysis. A single-mirror Goldmann contact lens (Ocular Instruments Inc, Bellevue, Washington) was used for gonioscopy on all subjects, and the anterior chamber angle was graded using the Shaffer system of classification. The clock hours for each grade were also recorded. Angles were considered open if more than 10 clock hours were clearly visible up to the scleral spur in each eye. We also looked for changes in the angle, including increased pigmentation, pseudoexfoliation (PXF) deposition, and PXF material within the angle during gonioscopy. Visual field examination was deferred for participants who either refused or had visual acuity less than 6/30 in the eye to be tested. All eligible participants underwent a Humphrey central 24-2 full threshold visual field test by the Humphrey automated perimeter (Humphrey Instruments Inc, Dublin, California). If the visual field was determined to be abnormal, unreliable, or both, testing was repeated on a subsequent day or on the same day after the subject had adequate rest. Criteria used to determine abnormality included an abnormal glaucoma hemifield test and a corrected pattern standard deviation \( P < .05 \). Criteria used to determine unreliability of the fields included false positives 50% or greater, false negatives 33% or greater, and fixation losses 50% or greater.

The definition of glaucoma used in this study did not depend on IOPs and required one or both of the following: (1) changes in the appearance of the optic nerve head due to glaucoma and (2) perimetric defects in the nerve fiber bundle pattern typical of damage from glaucoma. Subjects with a vertical cup-to-disk ratio of \( >0.8 \) or a narrowest neuroretinal rim width of \( <0.2 \) (including classic notching) or asymmetry \( >0.2 \) between eyes coupled with a visual field defect in the matching location were considered as cases of glaucomatous optic nerve damage. When visual fields were not available because of a subject’s poor visual acuity or poor reliability, the presence of significant optic disk excavation compatible with glaucoma, or end-stage glaucoma with severe central vision loss, or total optic disk cupping was sufficient for diagnosing glaucomatous optic nerve damage. Subjects with symmetric, large optic cups and
eyes with IOP greater than 21 mm Hg but without definite evidence of glaucomatous optic nerve damage were characterized as glaucoma suspects and advised to seek periodic ophthalmologic examination.

To be sure that individuals with mildly atypical findings or inconsistencies or missing data were not overlooked, all individuals with potentially abnormal visual fields were reviewed again clinically by two glaucoma specialists. Abnormal visual fields included abnormal or borderline fields on the glaucoma hemifield test and fields that were abnormal but incompatible with glaucoma. Available visual fields of an individual were compared with one another and with the appearance of the optic disk for compatibility. None of the subjects who were reviewed again met the definition of glaucomatous optic nerve damage, that is, a vertical cup-to-disk ratio >0.8 or a narrowest neuroretinal rim width <0.2 (including classic notching) or asymmetry >0.2 between eyes.

Definite POAG was defined as angles open on gonioscopy and glaucomatous optic disk changes with matching visual field defects. Ocular hypertension was defined as IOP greater than 21 mm Hg and open angles on gonioscopy without glaucomatous optic disk damage and visual field defects. Manifest primary angle-closure glaucoma was defined as (1) glaucomatous optic disk damage or glaucomatous visual field defects with the anterior chamber angle either partly or totally closed, appositional angle closure, or synechiae in the angle, and (2) absence of signs of secondary angle closure. Secondary glaucoma was defined as glaucomatous optic nerve damage or visual field abnormalities, or both, suggestive of glaucoma with ocular disorders that contribute to a secondary elevation in IOP.

Prior to ocular examinations, trained social workers conducted interviews to collect demographic and other details using a structured questionnaire. Information was collected regarding prior eye examinations, including service provider visited, the duration since the last examination, and the reason for an eye examination. Information was collected on whether people did not visit an eye doctor even though they had felt a need, and the reason for not visiting an eye doctor.

Persons requiring eye care in this study population were defined as persons with presenting vision in the better eye worse than 6/18 and/or a diagnosed ocular pathology after examination.

The study protocol was approved by the institutional review board of Johns Hopkins Bloomberg school of Public Health, Baltimore, Maryland, and Aravind Eye Care System, Madurai, India. The tenets of the Treaty of Helsinki were followed. Verbal informed consent was obtained prior to the study because a significant proportion of the population was illiterate.

Bivariate and multivariate logistic regression was performed to explore for associations with utilization patterns using STATA version 7.0 (College Station, Texas). We considered P values <.05 to denote statistical significance.

RESULTS

Of the eligible 5,539 persons aged 40 years or older, 5,150 were examined (a response rate of 93.0%). Three thousand four hundred and seventy-six (72.7%) of 5,150 subjects examined required eye care examinations. One thousand eight hundred and twenty-seven persons (35.5%) gave a history of prior eye examinations, primarily from a general hospital (n = 1,073, 58.7%). Table 1 shows the prevalence (95% confidence interval [CI]) of glaucoma in the study population. Sixty-four subjects had POAG. The prevalence of exfoliation in this population was 6.0% (95% CI: 5.3, 6.7). The median age of those with any glaucoma was 60.0 years (mean, 60.8 ± 10.1 years; range, 40-85 years), and 79 (60.0%) were males.

After best correction with refraction, 19 persons with POAG were visually impaired, including one person who was blind (best-corrected visual acuity <6/120 in either eye). An additional 12 persons had unilateral blindness due to glaucomatous optic neuropathy in that eye; thus 13 persons (20.3%) with POAG were blind in one or both eyes due to POAG.

Only 1,827 subjects had ever received any prior eye care. The most common reasons were lack of funds, time, or an escort.

There were 912 persons who felt that they needed eye care but did not seek it. Many reasons were given for this lack of care (Figure 4). The most common reasons for not obtaining care in this group were the lack of funds (78.2%) and the lack of time to come for an examination (70.0%).

Of the 132 persons with any glaucoma, 67 (50.1%) had never had an eye examination. Nineteen (14.4%) of the 132 persons with any glaucoma had their last eye examination within the 2 years immediately preceding our survey. Forty-five (34.1%) of the 132 persons with any glaucoma had previously been to a hospital, and an additional 21 (15.9%) persons had ever visited an eye doctor. However, only 11 (16.9%) of the 65 persons with glaucoma who previously had an ocular examination had received any treatment for glaucoma at the time of the survey. This included nine persons taking eye pressure–lowering medications and two persons who had a prior trabeculectomy. The odds of utilizing eye care services increased significantly with age (Table 2). After adjusting for age and sex, the odds for utilization...
increased with increasing education. Persons with unilateral or bilateral vision impairment or blindness were more likely to use services \((P < .01)\).

Of the 64 subjects diagnosed with POAG, 32 (50.0%) had never had an eye examination in the past. Although 7 (21.9%) of the 32 subjects diagnosed with open-angle glaucoma who previously accessed eye care services had an eye examination within the 2 years immediately preceding our survey, none of them had an eye examination within the 1 year preceding the survey. Only 6 (18.75%) of these 32 subjects who accessed eye care services had received any antiglaucoma treatment at the time of the survey; thus 93.0% of those with open-angle glaucoma had not been diagnosed until the survey.

**DISCUSSION**

The results of National Eye Institute–sponsored multicentered studies have all shown that adequate IOP lowering has the potential to prevent both the development and the progression of visual field loss leading to visual disability and blindness.\(^{23-25}\) That is, glaucoma is a treatable disease. The skills required to detect glaucoma are relatively simple and include measurement of the IOP and examination of the visual acuity, pupils, visual fields, and optic nerve. One can lower eye pressure and thus treat glaucoma in one of several ways: medications, surgery, or lasers. Lasers are not commonly available in rural India. However, eye pressure–lowering medications such as beta-blockers, alpha-agonists, and carbonic anhydrase inhibitors are commonly available at reasonable prices in India (less than US $1.00). Surgical skills to perform glaucoma filtration surgery are also commonly taught.

Even though medications and surgical skills to treat glaucoma are available, 30% of those detected in our study who had glaucoma were blind or visually disabled in one eye and 34% had severe visual field loss in both eyes. Low utilization of glaucoma eye care services, in a region where first-rate services are available, may be responsible

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**FIGURE 4**

Reasons why 912 persons in the Aravind Comprehensive Eye Survey who felt they needed eye care did not obtain it.

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**TABLE 1: PREVALENCE OF GLAUCOMA IN A RURAL POPULATION IN SOUTHERN INDIA, AGED 40 YEARS OR OLDER (n = 5,150)**

<table>
<thead>
<tr>
<th>TYPE OF GLAUCOMA</th>
<th>PREVALENCE (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open-angle</td>
<td>1.2 (0.9, 1.5)</td>
</tr>
<tr>
<td>Angle-closure</td>
<td>0.5 (0.3, 0.7)</td>
</tr>
<tr>
<td>Pseudoxfoliation</td>
<td>0.4 (0.3, 0.6)</td>
</tr>
<tr>
<td>Secondary</td>
<td>0.3 (0.2, 0.5)</td>
</tr>
<tr>
<td>Absolute</td>
<td>0.06 (0.0, 0.1)</td>
</tr>
<tr>
<td>Any type</td>
<td>2.6 (2.2, 3.0)</td>
</tr>
</tbody>
</table>

CI, confidence interval.

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**TABLE 2. ODDS RATIOS OF UTILIZATION OF ANY EYE CARE BY STUDY POPULATION IN RURAL SOUTHERN INDIA**

<table>
<thead>
<tr>
<th>AGE (YR)</th>
<th>ODDS RATIO*</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>50-59</td>
<td>1.2</td>
<td>1.0, 1.4</td>
</tr>
<tr>
<td>60-69</td>
<td>1.7</td>
<td>1.5, 2.0</td>
</tr>
<tr>
<td>≥70</td>
<td>3.4</td>
<td>2.7, 4.2</td>
</tr>
</tbody>
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*Reference category is 40 to 49 years of age.
for this dismal state of affairs. Many steps are needed to remedy this situation.

First, ophthalmologists must begin to educate individuals at an early age about the role of health care resources and how to better utilize them. People should be taught that blindness is not a normal part of aging and an expected outcome of older age. Marketing of health care availability and utilization, through videos, the media, and local religious and service organizations could also help. Better education about prevention of blindness, in a nation where blindness is so evident, might well help to minimize it.

People also need to be educated about the types of eye care providers. In the population studied, 39% of those requiring eye care services had sought some help, and almost 60% of these had gone to a general hospital, not an eye care provider. Less than one quarter had visited an ophthalmologist. Because of the relative paucity of ophthalmologists in India compared to developing countries, we must educate patients about the proper place to go for ophthalmic care and also educate other health care practitioners about diseases such as glaucoma, glaucoma screening, the fact that glaucoma can be successfully treated, and the ability of glaucoma to cause blindness.

As in more developed nations, finances can definitely influence the utilization of ophthalmic health care in developing countries. This can be a complex issue. During the period of the study, the Aravind eye care hospital system, which prides itself on giving high-quality cost-efficient eye care, offered such care at no charge to over one half of patients with no questions asked and gave free surgery to almost two thirds of all patients. In those who felt that they needed eye care, but who did not obtain it, it is important to note that the reasons given may be typical of a relatively poor agrarian society. Money is an obvious reason for not seeking medical care, but it becomes a thought-provoking cause when one notes that the actual eye care would have been free. Subjects may or may not have known that they could have received such free care at Aravind. However, we did not ask about or account for monies lost by the subject or accompanying family member by not earning a day's wage when visiting eye care facilities. Strategies to improve utilization should include education regarding the cost-efficient nature of obtaining appropriate health care relative to the costs of blindness. Many patients come to physicians with a family member accompanying them. This might be especially true of individuals with limited vision, needing guidance and help navigating the potentially dangerous southern Indian road and bus systems. The fact that escorts were not available for many suggests that improvements in transportation and support systems to obtain health care might be necessary to improve utilization.

We previously found that 3.14% of those individuals who are 60 years of age or older have glaucoma in this population. That this potentially preventable cause of visual impairment and blindness, which is relatively common in this older population, is grossly underdetected may suggest the need for better strategies to identify persons with glaucoma in rural India. However, there are several issues relating to screening for glaucoma to be considered. A major concern is the lack of a good method to screen for glaucoma in populations. The definition of glaucoma requires correlation with visual fields in all cases unless perimetry cannot be performed for any reason. Computerized threshold automated perimetry is costly and time-intensive, and it may not be feasible for eye care programs, particularly those catering to rural populations in developing countries. We reported earlier that a vertical cup-to-disk ratio of >2 SD may be an alternative measure to suspect glaucoma in this rural population. However, dilation would be required, and this may be difficult in this population, where clear media is not commonly present due to either cataract or corneal opacification. Intraocular pressure measurements are neither sensitive nor specific for glaucoma screening in this population.

Less than one fifth of those with glaucoma in our survey had been previously diagnosed as having the disease despite having had an eye examination in the past. The cross-sectional design of the survey does not allow us to determine if these subjects actually had glaucoma at the time of their examination, or if glaucoma had developed during the period since their last eye examination. However, the work of Wilson and others in St Lucia, West Indies, shows that if left untreated, glaucoma can frequently result in increased visual field loss and blindness. Our results suggest the potential need to revisit residency curricula and to ensure that every ophthalmologist becomes familiar with techniques and interpretation of perimetry, slit-lamp biomicroscopy, gonioscopy and classification of the anterior chamber angle, and applanation tonometry.

Training of human resources and development of infrastructure are currently the focus of initiatives against blindness, including VISION 2020 and the National Program for Control of Blindness in India. Results from our study, however, suggest the additional need to focus on developing strategies to improve utilization of existing services. The low utilization of eye care services, even in those who perceived a need in a region where free and good quality eye care is readily available, is quite disappointing. It is disconcerting to note that only one third actually had an eye examination at any time in
their lives, yet three fourths of persons aged 40 years or older in this rural population required eye care services. The number of persons who had had an eye examination in the previous year was only 15.1%. The need for strategies to improve utilization is further emphasized when we consider that none of the subjects with a diagnosis of glaucoma prior to our survey had had an eye examination within the previous year. The need for improved utilization assumes greater importance because recent reports have proven the efficacy of early intervention in reducing the potential for blindness in persons with glaucoma.\textsuperscript{23-25}

The results reported here suggest that the focus of eye care programs has to broaden beyond identification of cases of glaucoma if the burden of blindness due to glaucoma is to be reduced. Strategies for better education of patients and physicians and for better marketing of available services to improve utilization are urgently required to ensure follow-up and compliance to advised therapy.

REFERENCES

DISCUSSION

Dr Bruce E. Spivey. As one would anticipate, the work by Dr Robin and co-workers was scrupulously planned, exquisitely implemented, and thoughtfully presented. I will comment on the study and its approach only to say it is based on well accepted, previously described, and appropriate statistical, geographical, and analytical evaluation. This report adds substantially to understanding the barriers to eye care services in South India, previously noted to be the cost of services and access problems due to transportation and the lack of accompanying persons.

When we hear of South India and the state of Tamil Nadu, those unfamiliar may assume that there is little opportunity for eye care in the region. This is far from reality. The Aravind Eye Care system based in Madurai is the largest private eye care system in the world. Last year, the system saw more patients (1,480,012) and operated on more eyes (202,066) than any other eye system. As noted, they provide a free service for those who cannot pay. This means their findings have more profound and daunting implications than it would initially appear. Superb care is readily available in this state in India. Thus, the barriers are not the obvious: availability or even cost of care. The barriers, however, are fundamental and deeply based on the society, patient education, effective marketing, and family travel support.

The paper has implications far beyond glaucoma in South India. As the quality and availability of eye care is slowly improved throughout the world, there clearly cannot be even a minor victory declared when good quality, free, and available eye care does not translate directly to the successful treatment of preventable blindness. The implications are enormous. Ophthalmologists have traditionally felt that if they are in place with commitment and infrastructure, functional vision success will naturally follow. The Baltimore Eye Study has shown the same problems in the United States.

Strategies for involvement of community leaders (formal and informal), existing community services, intense outreach through marketing in all possible forms, and supportive transportation services are absolute necessities and must be considered an integral part of any eye care service program. It must truly be a team effort—planned and implemented with the same approach we take with eye surgery itself.

I recently had the opportunity to visit multiple ophthalmology training programs in Nigeria. Here the capacity is far less than what is available from the Aravind Eye Care System. The gap between what is available in almost all of sub-Saharan Africa and that in Aravind is far greater than that between Aravind and the United States.

Even an experienced observer with very substantial, credible time in the field such as Dr Robin, has not yet created a series of definitive steps that, if taken, would be successful. We have learned to provide efficient, effective, and low cost (even free) eye care. We have not yet learned how best to ensure those who actually need that care will avail themselves of the availability.

Dr George L. Spaeth. We have to think frequently about what we are here for. Presumably, one of the reasons is to try to prevent people from going blind, or, even more pertinently, to increase their quality of life. Dr Robin did not mention some of the other studies that have been done recently by David Friedman of Wilmer and by Rohit Varma of Los Angeles. Dr Varma has recently shown that in Hispanics, the increase in the prevalence of glaucoma is so great with increasing age that it gets to be 24 percent in individuals over 80. In blacks, the increase is almost, but not quite, as exponential. These are the two groups that are undergoing a significant worldwide increase in population. We literally are having an epidemic of glaucoma. Jeff Henderer at Wills has been interested in how to get people into care. He did a study recently where he went to church groups in Philadelphia, realizing that people are likely to have some kind of tie-in, and then screened people for glaucoma. The church people were addressed by a doctor and by a social worker, were given an appointment, and then were given a voucher for free travel to the hospital. Only 11% came for the appointment. When we consider the amount of resources that are being put into studying matrix metalloproteinases in comparison to preserving sight, how do we start all over?

Dr Dennis M. Robertson. Aravind Eye Hospital, which can be regarded as a model of eye care for the world, has 1,000 beds for eye patients; it is an amazingly effective system of eye care in large part because the staff who work there are spiritually dedicated to the whole movement of saving sight in India. Most of the people who are working there have had an opportunity to practice in other environments; some have had successful practices in the United States but they returned to India to work for very little monetary reward. The success of Aravind is not only because of the spiritual dedication of the people on the staff but also because of the help from other people. For example, Suresh Chandra, who has been with Combat Blindness, has helped develop a manufacturing plant at
the Aravind site that produces intraocular lenses for approximately $5. They now supply about one-third of the world’s intraocular lenses; with the income from lenses that are sold and from the income from those patients who can pay, they have been able to provide care for many who have no means of paying for their care.

DR JOHN T. FLYNN. The best reason why there are starving human beings in the midst of plenty is because of poverty. About two months ago, there was an editorial in the New England Journal of Medicine where an internist had the job of telling a 24-year-old Hispanic woman, mother of two or three children, that she had AIDS. He went through a tremendous examination of his conscience and how terrible he felt about this. When he told her, she just sort of brushed it off. Why did she brush it off? Because she had family problems, economic problems, work problems, drug problems that were so staggering that the diagnosis of AIDS—which is essentially today a sentence of death, even though it’s prolonged life—meant little or nothing to this woman. Unless we address the socioeconomic basis, which is poverty, we’re never going to change the way they access the healthcare system.

DR EDWARD L. RAAB. I recently had the privilege of doing two separate volunteer faculty tours for ORBIS in India, and I can tell you that what you describe is common in other areas of India as well. I was most recently in West Bengal, and your description matched with the situation there very well. One of the things that impressed me was the compliance issue, and it makes me now distinguish between the two types of non-compliance. One is willful non-compliance, or neglectful non-compliance, and the other is logistical non-compliance. People have to be in the fields working, they don’t have money to get to where they have to go or to obtain the necessary treatments, and that is a much larger problem in the area where I worked than was willful non-compliance. Maybe the distinction between those two concepts would be useful in describing some of your data.

DR ALAN L. ROBIN. I thank Dr Spivey for his thought-provoking and excellent initial discussion and I’d like to agree with all the comments by the other discussants. The question of how do we go about changing behavior is really the most fundamental question that should engage us as leaders. Dr Spaeth’s comment about the allocation of research funding is a very important issue. We must re-examine our priorities. I believe that the most important question facing our current advanced medical system is the question of how to get patients who should be in the system, with real pathology, into facilities that can render good quality care. I think the last comment about the universality of the problem is true. If it happens in Baltimore, in West Bengal, and in Madurai, then it is a universal problem. The Gurwitz study (1993) found that the mean number of days of missed glaucoma therapy in 2,440 patients was 112 days per year. Mark Preslan found that parents, even when given free care, social workers’ assistance, and free spectacles, did not utilize this care and allowed their children to become amblyopic. What about physicians’ families and their compliance patterns? There have been compliance studies looking at physicians’ wives and how they comply with amoxicillin therapy for their children with otitis media. In this group of potentially well-motivated and well-educated people, nearly 80 percent of the mothers did not fully comply with the antibiotic regimen. The AREDS data found that only 75 percent of patients in the AREDS study fully complied with the vitamin regimen. Following the study, less than one-half of this group of well-motivated individuals complied.

Debra Roter at our Johns Hopkins Bloomberg School of Public Health did a study that investigated how well patients heard what doctors told them when their medications were changed. During doctor patient interactions, a tape recorder actually recorded all instructions. Patients were then interviewed and approximately 60 percent of the patients did not remember that the doctor had changed their therapy.

How can we change this behavior and improve utilization of available resources, compliance and adherence? I think we have to market good quality care! India is the biggest user of videos in the whole world (Bollywood). If one could put a leader on every one of those videos that related the appropriate use of eye care facilities and this would train individuals that losing vision is not a normal part of growing old, it would be a tremendous step toward eradicating blindness. Efforts like those of Bruce Spivey, George Spaeth, and others in this room are needed to educate patients that their own efforts can prevent some of their own visual disability so that potentially they can maintain their independence and improve their quality of life.