Perceived Causes of Loss of Vision and Areas of Potential Intervention in Glaucoma from Patient, Family Member, and Eye-Care Provider Perspectives: A Focus Group Study

By

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Introduction

Glaucoma is a leading cause of blindness among older adult Americans. Despite the practice of evidence-based treatment for glaucoma there exists a high rate of failure to prevent loss of vision, even in patients receiving current glaucoma care. Non-compliance has received the greatest attention in the literature with respect to measurable factors associated with loss of vision in glaucoma. However, in order to improve glaucoma care and minimize preventable vision loss, further investigation is needed into the range of additional and underlying factors that may not be quantifiable in nature.

This study used qualitative methods using procedures of focus groups to obtain original source data from glaucoma patients, their support systems (family members and friends), and glaucoma eye-care as to why vision loss occurs in glaucoma patients and what areas may be a point for intervention. The purpose of this study was to characterize potentially new content areas and expand upon those previously suggested for intervention or additional investigation with respect to factors associated with vision loss identified by these focus groups.

Burden of Glaucoma

Vision loss among the elderly population in the United States is a significant problem facing public health. The population of elderly Americans is increasing rapidly and is estimated to approach 70 million within the next twenty-five years. Approximately one-third of the elderly population is afflicted by an eye-disease resulting in visual impairment, and over the next 30 years the number of Americans with visual impairments could double.¹ Loss of vision is associated with decreased social function
and ability to perform daily living skills,\textsuperscript{2} loss of independence and mobility,\textsuperscript{3,4} and increased depression.\textsuperscript{5} In a recent survey, elderly Americans reported loss of vision among their greatest fears. Furthermore, based on data from a report titled, "Economic Costs of Visual Disorders and Disabilities: United States, 1981," in 2003 the National Eye Institute (NEI) estimated current economic burden associated with ocular morbidity in the U.S. at $67.6 billion in total costs including both direct medical costs and indirect costs such as loss of wages, disability, and institutionalization.\textsuperscript{6} Most recently, Prevent Blindness America (2006) estimated the annual economic impact of adult visual impairment in the U.S. to be $51.4 billion in financial burden to the economy as well as medical care costs and health utility loss for the individual patient, caregivers, and healthcare payers.

Among patients with diagnosed visual disorders, between the ages of 40-64, direct annual medical costs for outpatient, inpatient, and prescription drug services associated with glaucoma are exceeded only by refractive error.\textsuperscript{1} When the age group is expanded to additionally include patients greater than 65 years of age, the total direct medical costs associated with glaucoma is ranked third among visual disorders exceeded by refractive error and cataracts, but remains associated with the greatest number of prescribed medications for all visual disorders among both age groups (40-64, and >65).

Glaucoma is a leading cause of vision loss among elderly Americans, and is the most common cause of blindness among older black Americans. The most recent estimate of prevalence for adults 40 years of age or greater with open-angle glaucoma in the U.S. was 1.86 percent.\textsuperscript{7} In 2002 the NEI reported that 2.2 million Americans have been diagnosed with glaucoma, and another estimated two million are affected but do not
know they have it. Furthermore, among those who have been left legally blind due to glaucoma, approximately 75 percent are over 65 years of age. As the elderly population continues to grow, this number will increase.

**Glaucoma Treatment and Vision Loss**

Glaucoma is a chronic and progressive disease that results in increased intraocular pressure and ultimately optic nerve damage and visual field loss. Frequently, patients with glaucoma are initially asymptomatic and only begin to experience symptoms, such as significant blurred vision or diminished visual field, late in the progression of the disease at which time functional loss of vision is not recoverable. Retrospective analysis has identified several quantifiable risk factors associated with progression of visual field loss to blindness, including: poor compliance, increased age, greater initial visual field loss upon presentation, and higher variability in intraocular pressure (IOP) during treatment.\(^8\)\(^9\)

At the present time, reduction and control of IOP is the only clinically modifiable factor demonstrated to slow progression of glaucomatous optic neuropathy and associated loss of vision in glaucoma.\(^10\)-\(^12\) Data exists for the relative effectiveness of specific treatments and procedures to lower IOP across the spectrum of disease severity from glaucoma suspects and patients with ocular hypertension, to patients diagnosed with early, moderate or advanced glaucoma.\(^1\) Historically, treatment and management of glaucoma has focused on sustained IOP values of less than 21mmHG or a target reduction in IOP of 30 percent or more, which is associated with lower probability of optic disk pathology.\(^10\)-\(^15\) Studies have additionally demonstrated an association between
diurnal fluctuations in IOP and progressive visual loss in glaucoma, specifically that minimizing variance in IOP fluctuation improves outcome in glaucoma.\textsuperscript{16-19}

Topical pharmacotherapy is highly efficacious and remains first-line treatment for glaucoma. However, we also know that clinical effectiveness of glaucoma treatment real-world practice outside of controlled clinical studies deviates from these ideals. Specifically, several retrospective cohort studies of glaucoma patients have demonstrated that despite our clinicians’ best efforts to provide efficacious medical and surgical therapy, some patients progress to blindness.\textsuperscript{20-22} For example, Hattenhauer et al. (1998) calculated that in a population of newly diagnosed glaucoma patients the probability of progression to legal blindness resulting from open-angle glaucoma (OAG) in at least one eye to be 27\% at 20 years even with medical treatment, surgical intervention, or both.\textsuperscript{23} Similarly, Chang et al. (2005) also estimated that despite glaucoma treatment the probability of developing blindness in at least one eye due to glaucoma was approximately 29\% at 16 years.\textsuperscript{24}

Studies using blindness as a main outcome measure generally do not include assessment of progression of functional vision loss as an additional outcome measure. Therefore, the proportion of patients affected by progressive and continued vision loss resulting from OAG is likely greatly underestimated by these figures. For example, in a study assessing progression of visual loss in a population of patients with diagnosed or suspected glaucoma, Wilson (2002) demonstrated that 16\% based on Advanced Glaucoma Intervention Study (AGIS) criteria and 35\% based on Collaborative Initial Glaucoma Treatment Study (CIGTS) criteria of those with untreated glaucoma would advance to end-stage glaucoma in at least one eye over 10 years. However, over this
same interval continued progression of visual field loss by AGIS criteria occurred in 54% of total eyes included in the study. Additionally, independent studies have reported visual field loss rates of approximately 2% up to 5% per year in glaucoma patients even when receiving specialist care. However, survey data suggests patients may hold a different perspective of this risk over time. For example, at the time of diagnosis, 34% of glaucoma patients enrolled in the CIGTS reported at least moderate fear of blindness; however, over a five year period of time, this decreased to only 11% despite evidence demonstrating sustained risk of progressive visual field loss.

Collectively these studies demonstrate a critical need to understand why patients may not receive or may not optimize use of efficacious glaucoma care. The specific factors involved in providing optimal individualized care that result in best patient-centered treatment outcome are likely complex, interrelated, and poorly understood. To date, emphasis has been placed on patient non-compliance with recommended care as a postulated major contributing cause of loss of vision in glaucoma, with estimates of patient non-compliance ranging anywhere between 5 and 80 percent. Although non-compliance is clearly a factor associated with loss of vision in glaucoma, it likely serves as an intermediary but not "root cause" of loss of vision and further fails to provide descriptive and qualitative information necessary to identify underlying factors.

Contributing factors may not be limited to patient-specific behavior, and may extend into the capacity of family members, eye-care providers and even the health care system. For example, content areas warranting specific interest may include preferred patient-physician relationship styles (e.g. provider honesty and understanding), preferences and expectations in treatment (e.g. involvement in care), and level of
knowledge or understanding of disease (e.g. learning style for receiving and assimilating information). 30-33

Purpose of the Study

The purpose of this study is to qualitatively capture a broader as well as deeper insight into factors and barriers identified in vision loss in glaucoma patients despite receiving recommended and appropriate clinical care and also to identify additional areas for possible investigation and intervention to optimize glaucoma treatment and reduce vision loss. Accordingly, development of a more comprehensive understanding may be best accomplished through direct solicitation of information from multiple stakeholder perspectives such as: glaucoma patients; patients’ family or friends that serve as primary support system or caregiver; and ophthalmologists or optometrists providing glaucoma care.

In order to approach this, we sought to use focus groups to obtain this information. Focus group design is an established and useful tool for collecting and evaluating this type of qualitative information. Specifically, this format promotes detailed description of individual and group perspective as expressed directly from the subjects themselves.34 In the present study, use of focus groups facilitated identification of unique experiences and insights held by glaucoma patients, their family members and friends, and eye-care providers involved with glaucoma patient care. The content area analysis provided information regarding concurrence as well as discordance between patient, family member, and provider deeper perspective into specific causes of loss of vision in
Methods

Study Participants

Recruitment for focus group participants occurred at three collaborating teaching university ophthalmology centers: The University of California in Los Angeles; Duke University in Durham, NC; and The Mayo Clinic in Rochester, Minnesota. This study was approved by the Duke University Institutional Review Board (protocol #364983ER). Efforts were made during recruitment to include participants that were representative of both genders, a range of ethnicities, and diverse socioeconomic and educational backgrounds when applicable. For this study, three specific types of focus groups included: glaucoma patients with varying degrees of vision loss, family members and friends of glaucoma patients that were involved in their lives, and eye-care providers that treated glaucoma patients, including optometrists, general ophthalmologists, and glaucoma specialists.

Participant Inclusion Criteria

General criteria for participation in any focus group type included: greater than 18 years of age, proficiency with the English language, and ability to provide informed consent. Specific requirements for participation in the glaucoma patient focus group were prior diagnosis of glaucoma with varying severity of loss of vision, no confounding ophthalmologic conditions causing loss of vision (LOV) (e.g. Age-related Macular Degeneration, Proliferative Diabetic Retinopathy), and under current treatment for glaucoma, and provided focused areas of potential intervention to minimize its occurrence.
glaucoma. In order to maximize patient comfort with respect to participation, patient focus groups were organized to by two criteria: whether significant visual loss had occurred for the glaucoma patient, and their level of education, and groups were composed of members with similar visual status, and additionally with similar educational background when possible. In addition, eye-care providers were not present at any of the patient focus groups sessions in order to encourage participants to feel comfortable and be forthright in discussion topic responses.

Additional criteria for participation in the family member and friend focus group were: (1) lives with a person diagnosed with glaucoma and provides them assistance; or (2) functions as the primary family member responsible for the person (if not living in same household); or (3) functions as the primary and direct support structure for the person (if not living in same household). Eye-care providers were not present at any of the family member and friend focus groups sessions.

Participation in the eye-care provider focus group required current board-certification and state licensure in their given occupation, minimum of 5 years since completion of training, and provision of glaucoma care accounting for greater than 20% of their practice.

Focus Group Procedures

A standardized semi-structured script, specific to each focus group type, based in part on a previous visual function study funded by the National Eye Institute (1998) and prior standardized protocols,19 was employed at each site during every focus group session to guide discussion. Prior to focus group sessions, nine pilot interviews were
performed across the participating sites (three per site) to ensure that topics were appropriate and clear, and were additionally used to revise the focus group script. The resulting focus group topic questions were derived and reviewed by all of the study investigators involved in creating the script. During each focus group session, a trained facilitator or moderator was present whose role was to initiate and help direct conversation and participation through a specific scripted series of questions. These facilitators received standardized protocol training by one of the study principal investigators and were not directly involved in delivery of glaucoma patient care.

The general topic for the patient, the family member, and the eye-care provider focus groups was related to why patients with glaucoma might lose vision. To relieve formality, focus group sessions generally began with introductions and sharing of personal experiences with respect to glaucoma. During discussion, general standardized probes were presented as open-ended questions with respect to loss of vision in glaucoma patients and potential ways to improve patient outcome. Additional specific probe question topics were guided by possible factors identified in previous studies. These topics included: general knowledge of glaucoma and treatment, specific perceived causes of glaucoma treatment failure and loss of vision, expectations of care and treatment, and specific actions that could minimize loss of vision in glaucoma. Throughout all sessions, probe questions were presented to the focus group as a whole, and participants could chose whether or not to provide a response. Respondents were encouraged to be wide-ranging and elaborative in their personal experiences, comments, and suggestions. All focus group sessions were either audiotaped or videotaped, and were then directly
transcribed verbatim. Only the first names of participants were used as personal identifiers during focus group sessions to prevent potential linkage to patient charts.

**Focus Group Content Analysis Procedures**

Transcripts from focus group sessions were initially reviewed to identify any and all possible responses to the given probe questions and were then further examined for common categorical themes of comments. Subsequently, all remaining potential participant identifiers were removed when all comment taken directly from the transcripts were first coded and then organized into mutually exclusive response categories based upon the main theme of response with respect to the question of interest. Specifically, content analysis was performed on the coded data to determine the frequencies of response categories within a specific focus group type and for comparison between different focus group types. Samples of transcripts from patient, family member and friend, and eye-care provider focus groups, were independently reviewed by various research members to evaluate reviewer correspondence. For the purposes of self-validation, kappa statistics were calculated at greater than 0.70 for independent reviewer agreement on a sample of transcribed data; however, due to the qualitative nature of this study and use of nominal categories to organize data, this was not necessary or especially informative for the data analysis and reporting.35

**Results**

**Focus Group Participant Characteristics**

A total of 26 glaucoma-specific focus groups including patient groups, family member groups, and eye-care provider groups were conducted at three collaborating
teaching university ophthalmology centers. The geographic locations of these centers included: Los Angeles, California; Durham, North Carolina; and Rochester, Minnesota. Characteristics of the focus group types are described in Table 1.

Perceived Causes of LOV

*Patient Focus Groups*

Within patient focus groups, 61 comments with respect to perceived causes of loss of vision (LOV) in glaucoma were categorized into nine distinct response categories (Table 2). The categories for causes of LOV reported by patient focus groups from most to least common included: patient non-compliance; being “unsure”/uncertain of the causes; cost of medications and related care; being unaware of consequences due to asymptomatic nature of glaucoma; lack of continuity of care or change of eye-care provider; missed or delayed diagnosis; lack of education; uncontrolled IOP; and “optic neuropathy”. Comments emphasizing patient non-compliance with medication regimen and routine recommended care (e.g. complexity of medication routine, difficulty with application of medications, side effect profiles, and keeping up with appointments) constituted more than a third of responses (36%). Within the set of reported factors related to LOV, those that demonstrated an understanding of the disease process involved in glaucoma were least reported, for example, uncontrolled IOP (3%) or “optic neuropathy” (3%). However, the patient group provided a unique response category related to causes of LOV in glaucoma, namely, that change of eye-care providers was an important factor (10%).

*Family Member and Friend Focus Groups*
Compared to patient and eye-care provider groups, the family member and friend focus groups provided the fewest number of total comments (16) as well as distinct response categories (4) regarding perceived causes of LOV in glaucoma (Table 2). The most frequently reported response categories were: being “unsure”/uncertain of the causes of LOV (50%), followed by the cost of glaucoma medication and associated glaucoma care (25%). Comments by family member and friend focus groups that were categorized into the “unsure” response category included mainly descriptions of personal lack of knowledge with respect to causes of LOV in glaucoma. Comments also included those suggesting the patient him/herself did not know the causes of glaucoma-related LOV or that the patient with whom they were directly involved had information about their glaucoma but “kept information” from the family members and friends. Except for those personally diagnosed with glaucoma, family members and friends confirmed having little general familiarity with respect to glaucoma, treatment, and its effects on vision.

**Eye-Care Provider Focus Groups**

The eye-care provider focus groups produced the greatest number of total comments (77) and distinct response categories (11) with respect to perceived causes of LOV in glaucoma (Table 2). The causes of LOV reported by eye-care providers in decreasing frequency included: patient non-compliance; delayed or missed diagnosis; cost of related care and medications; patients being “unaware” due to asymptomatic nature of glaucoma; lack of patient education; provider avoidance in relaying “bad news” to the patient and family; lack of appropriate referral either from primary care provider to ophthalmologist, or from general ophthalmologist to glaucoma specialist; absence of
available “cure”; patient has other more serious medical problems; IOP is not a meaningful measure of patient outcome; and being personally “unsure” or uncertain. The eye-care providers reported five unique response categories concerning perceived causes of LOV not included in the patient or family member focus group response sets, most of which centered on clinical issues at the provider or health system level: provider avoidance, lack of appropriate glaucoma referrals, absence of available “cure”, patient has more serious medical issues, IOP is a poor measure of patient outcome.

Recommended Potential Areas of Intervention

Patient Focus Groups

Patient focus groups mentioned 24 total recommendations regarding areas for potential intervention to reduce LOV in glaucoma that were organized into four distinct response categories (Table 3). These recommendations included from most to least common: improving patient education about glaucoma and medication compliance; closer patient follow-up by providers; provider honesty with patient and relationship of trust; and provider sensitivity and interest in the individual patient. One-half of all comments with respect to suggested areas of intervention focused on improving of patient education. It was explicitly recommended that eye-care providers present both general information about glaucoma care and the consequences and effects of non-compliance with medications and recommended care. Additionally, patients emphasized the importance of receiving information concerning diagnosis and treatment at a level comprehensible to them. For example, most patients described being presented with
information that was either too complex (e.g. “too much” or “too detailed”) or inadequate (“not enough” to understand).

Family Member and Friend Focus Groups

Family members suggested the fewest number of total comments (14) and response categories (3) concerning potential areas of intervention aimed to reduce LOV in glaucoma (Table 3). Potential actions suggested by family members to reduce LOV in glaucoma from most common to least included: increasing family member education and involvement; improving patient education about glaucoma and treatment; improving provider honesty and trust with the patient and family. Although the recommendation to improve patient education and provider honesty was the most common recommendation provided by family member groups, increasing or improving family member education and involvement was not a recommendation reciprocated by the patient groups.

Eye-Care Provider Focus Groups

Eye-care providers suggested the greatest total number recommendations (40) and response categories (13) regarding potential areas of intervention to reduce of loss of vision in glaucoma patients. Most to least commonly suggested actions that overlap with patient or family member recommendations included: closer patient follow-up by providers; improving patient education about glaucoma and medication compliance; provider sensitivity and interest in the individual patient; provider honesty with patient and building a relationship of trust; and greater family education and involvement. Although recommendations by eye-care providers demonstrated concurrence with those supplied by patient and family members, eight unique response categories for areas of potential intervention are shown in Table 3. These areas for intervention focused on
provider care practices and education, as well as changes within current health care
delivery practices. Specific comments and recommendations related to provider practices
included: tighter follow-up with their glaucoma patients including periodic “medication
checks” and “appointment reminders”; and improving physician-patient relationship
through attention to the individual needs and preferences of patients. Specific
recommendations related to health care system practices included: increasing rates of
referrals for specialized glaucoma care; “standardizing glaucoma care” to reduce
provider-reported variation in care across eye-care professionals; and increasing public
awareness of glaucoma through media campaigns.

Discussion

This study revealed some interesting general patterns in distribution of response
categories across focus group types. Not surprisingly, regarding perceived causes for
LOV the greatest number of total responses and distinct response categories were offered
by eye-care provider groups, followed by patient focus groups, while the fewest were
offered by family member focus groups. As demonstrated in Figure 1, patient focus
groups uniquely reported frequent change in eye-care providers as a perceived and
preventable cause of LOV in glaucoma, eye-care provider focus groups offered several
unique response categories that accentuated eye-care provider and healthcare-centered
topics, and family and friend focus groups did not offer any unique response categories.
Overall, emphasis was placed on the following preventable causes of LOV in glaucoma:
cost of glaucoma-related care, patient non-compliance, and being “unsure” of or unable
to identify any causes.
With respect to recommendations for potential areas of intervention, the greatest number of total responses as well as distinct response categories were provided by the eye-care provider groups compared to the fewest responses provided by the family member and friend groups. Again, the eye-care providers also contributed the greatest number of unique recommended response categories, mainly focusing on issues related to the delivery and allocation of healthcare services (Figure 2). All three types of focus groups emphasized the following major areas of potential intervention to minimize LOV in glaucoma: patient education and involvement in glaucoma care, and provider interpersonal and communication skills.

Cost of Care

Cost of glaucoma-related care was among the top three perceived causes of LOV in glaucoma cited by patients, family member or friends, and eye-care providers. Independent reporting across focus group types identifying cost as a major factor indicates this is a widely recognized problem. In 2007 Prevent Blindness America reported for patients 40-64 years of age with diagnosed visual disorders, glaucoma-related direct annual medical costs for outpatient, inpatient, and prescription drug services were exceeded only by refractive error, and glaucoma was also associated with the greatest number of prescribed medications for all visual disorders. Survey data clearly demonstrates that older patients with chronic illnesses requiring prescription medications admit to intentionally underusing prescription medications in order to reduce the financial burden.
Cost of glaucoma-related care may be of special concern for the population of patients most affected by glaucoma, namely the elderly that frequently rely on Medicare coverage for health care services and medication. Continued efforts should be placed on reducing medication costs; and developing appropriate and cost-effective screening methods to improve early detection of glaucoma, thus avoiding the formidable cost of care and associated burden of advanced glaucoma. Importantly, eye-care providers should initiate open discussion with patients regarding their financial situation and ability to pay for their medications to accomplish several goals: to identify those that require and may qualify for assistance programs, to minimize potential cost-associated issues of non-compliance, to demonstrate personal interest and concern for the patient.

Non-Compliance

Patient non-compliance with medical treatment was the most frequently reported perceived preventable cause of vision loss in glaucoma reported by both the patient and eye-care provider groups, 26% and 31%, respectively. Based upon large randomized controlled trials, use of topical hypotensives for medical management of glaucoma is considered first-line therapy, and not surprisingly, it is common for patients to require multiple medications used in complex schedules of administration. Perception of non-compliance contributing to LOV by patient and eye-care provider groups is consistent with previous research that reveals estimated alarming rates of non-compliance as high as 80% in glaucoma patients. Currently, the threshold for compliance required to achieve clinical effectiveness in reducing progression of visual field loss remains unquantifiable, thus the ultimate clinical consequence is unknown, demonstrating the need for further insight into non-compliance.
The present study format was useful in describing specific challenges that underlie patient non-compliance, as reported directly from glaucoma patients. The five most commonly identified specific barriers to compliance included: inconvenience or complexity of medication routine, difficulty in instillation of medication to the eye, physical discomfort or side effects of medication, frequent changes to medications, and difficulty in maintaining appointments. Upon further explanation, patients expressed great concern that increased reliance (“being dependent”) on friends and family for assistance and transportation due to their declining vision was a specific barrier in ability to effectively self-administer medications, attend scheduled appointments, and even read appointment slips. Despite increased dependence on others, patients did not desire increased involvement or education for their family members or friends with respect to their glaucoma. This presents an opportunity for eye-care providers to investigate potential clinical management strategies that maximize patient autonomy.

Uncertain of Causes

Reporting that they were “unsure” or lacked knowledge of the causes of preventable vision loss in glaucoma was the most frequent response provided by family members or friends (50%), and the second most common response provided by patients (13%). In contrast, eye-care providers rarely reported this response. This is surprising considering that all of the patient participants were under current glaucoma care and all of the family member and friend participants were associated with patients under current care for glaucoma. In addition, the minimum reported time since receiving a diagnosis of glaucoma was five years and the maximum was 43 years, thus uncertainty with respect to
causes of LOV was not a function of a “new” glaucoma diagnosis. This finding is consistent with a recent cross-sectional study that demonstrated patients with established glaucoma have only slightly greater knowledge than newly diagnosed patients.40

Furthermore, when asked to describe their personal level of knowledge of glaucoma, effects on vision, and treatment, patient participants self-reported degree of knowledge ranging from “very little” to only “some”. No patients described their personal knowledge as greater than “some.” These comments suggest a significant disconnect in dissemination of information that may be occurring at several potential levels including: general public knowledge, primary care providers, eye-care providers, glaucoma patients, and family members or friends of glaucoma patients. Glaucoma knowledge could be improved through various educational measures such as public awareness campaigns, direct patient and family member and friend education, and various educational materials.

Education

Issues regarding the lack of knowledge about glaucoma, its effects on vision, and treatment, as well as non-compliance may be approached through mechanisms of patient education. Patient education was the most commonly recommended potential area of intervention by patient groups (50%) and the second most commonly recommendation by family member or friend groups (29%) and by eye-care provider groups (13%).

Patient comments specifically highlighted the need to improve patient education and knowledge with respect to glaucoma as a chronic disease, compliance with treatment, and consequences of inadequate treatment on vision. Many patients described personal
experience with being presented information that was inappropriate for their individual comprehension level or learning style (“too much” or that they “didn’t understand”), and factors such as comprehension and literacy have been recognized correlates of patient compliance and outcome. Of additional interest was the great variance in the “amount” and the “detailedness” of information desired by patients with respect to their disease and treatment. Eye-care providers echoed these specific recommendations and further suggested that information about glaucoma, vision, and treatment, should be presented to patients in a meaningful way, for example, in terms of functional visual outcome rather than perimetry tests or relative IOP values. This is consistent with survey data from The Collaborative Initial Glaucoma Treatment Study that showed anxiety and fear of blindness in newly diagnosed glaucoma patients was highly correlated with self-perceived visual function and not by clinical measures.

Collectively, this original-source data demonstrates a failing of our healthcare system to deliver information that is understandable and appropriate in format for this population of patients. Further, it calls to question whether the individual provider or health system is overestimating the “medical literacy” (ability to understand medical information and instructions) of these elderly patients. Glaucoma patient and caregiver education could be improved through use of patient health educators that offer individualized information as seen in management of diabetes, simplification of educational materials, and diversification of accessible educational resources.

Patient responses as well as eye-care provider responses also suggested educational interventions for physicians, such as training in continuity of care, and appropriate processes for referrals to specialists. Specific recommendations included that
eye-care providers be up-to-date in current standards of care for diagnosis, treatment, and management of glaucoma, and general practitioners recognize when it is appropriate or necessary to refer patients to eye-care specialists without delay. Interestingly, as a proposed measure to reduce loss of vision in glaucoma, family members and eye-care providers also recommended increasing family education and involvement in patient care; however, no patients made such suggestions.

Patient Involvement

Although there was general agreement among the patient groups and eye-care provider groups that patients should receive closer follow-up for glaucoma care, there was discordance in the extent of desired patient involvement in their care, specifically with respect to decision-making in treatment choices. For example, consistent with the popular patient-integrated movement in health care that imposes active participation by the patient in decision-making, the eye-care providers in this study stressed the importance of patient involvement in decision-making processes.\(^{44}\) In contrast, patients expressed tremendous variance in the extent of desired level of involvement ranging from preference to self-determine treatment plan, to preference for being informed and actively making joint decisions with provider, to preference for provider to make treatment decisions on the patient’s behalf (“tell the patient what to do”). This finding of great variance in individual patient preference for involvement in eye care is consistent with previous patient expectation studies regarding eye care.\(^{32}\)

Thus, patient preference for involvement in care deserves careful provider consideration especially when making decisions regarding long-term management of a
chronic disease such as glaucoma. Furthermore, providers must be cautious with respect to generalizing this desire to function as “active participants” to glaucoma patient populations whom are frequently elderly with multiple comorbidities and variable cognition and literacy. Although the concept of patient-integrated medicine may approach the theoretical ideal, it may not coincide with the desires or cognitive or functional capabilities of the individual patient.

Patient-Provider Relationship

Improving what can be described as the eye-care provider-patient relationship through provider honesty and provider sensitivity and personal interest in the patient was commonly suggested as an area of intervention to reduce preventable LOV in glaucoma. Establishing or increasing provider honesty with the patient and family was recommended by the patient groups (13%), family member and friend groups (29%), and eye-care provider groups (10%), and increasing provider interest in the patient and demonstrating sensitivity was suggested by the patient groups (13%) and the eye-care provider groups (13%). In other studies, such factors have been characterized as provider interpersonal and communication skills and have been positively correlated with patient satisfaction with eye care, and likeliness to comply with treatment and be forthright with respect to reporting compliance. In addition, some subpopulations of non-white patients have even described lack of provider trust and honesty as an obstacle to receiving eye care. In this study, patients highlighted several specific areas of improvement within the patient-provider relationship, such as demonstrating patience, providing honest opinion or assessment, and spending adequate time addressing any patient concerns. Of
interest was that eye-care providers emphasized the great importance of provider honesty despite also acknowledging hesitancy in being completely forthright when forced to bear bad news to patients and families.

Limitations of the Study

The patient population and their family members and caregivers consisted of those receiving care or associated with a patient receiving care at an academic eye-center, thus the generalizability of these findings to other patients and their family members and caregivers receiving care in a community-based or non-academic eye clinics is unknown. Although efforts were made to approximate equal gender representation within focus group types, compared to the general population there was greater female representation in the family member and friend groups, and less male representation in the eye-care provider focus groups. However, the gender distributions in these two focus group types may actually translate to an approximation of the glaucoma family member and caregiver as well as eye-care provider populations, respectively. Gender bias could potentially cause over- or under-representation of the frequency of certain response categories; however, this would unlikely affect the range of elicited responses.

Conclusion

A challenge faced by ophthalmologists in treating patients with glaucoma is how to provide optimal, effective long-term care that minimizes preventable loss of vision commonly observed in clinical practice. The objective of this study was to improve our qualitative understanding of contributory factors associated with loss of vision in
glaucoma patients despite receiving treatment and to elicit potential areas of intervention
to reduce this LOV. Use of patient, family member and friend, and eye-care provider
focus groups appeared to be valuable in emphasizing and expanding upon specific
components that underlie previously recognized and emerging concepts for approaching
the problem of preventable vision loss in patients receiving treatment for glaucoma. Of
special important for further investigation are ways to identify and apply patient
preferences with respect to management and treatment of glaucoma, in specific areas
such as: patient education style,\textsuperscript{31, 42, 43} patient involvement in care,\textsuperscript{32, 44} and characteristics
of provider-patient relationship.\textsuperscript{30-33, 45}
Acknowledgement

I would like to thank Dr. Paul Lee, Dr. Diane Calleson, Dr. Leon Herndon, Dr. Anne Coleman, Dr. Douglas Johnson, and Dr. Alfred Reid, whose continued support and assistance made this project possible.
Table 1. Focus Group Participant Characteristics

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Table 2. Perceived Causes of Loss of Vision

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<th>Perceived Cause of LOV Response Category</th>
<th>Group-Specific Responses n (%)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patients</td>
<td>Family Member/Friend</td>
<td>Eye-Care Provider</td>
</tr>
<tr>
<td>Change of Providers</td>
<td>6 (10)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Unsure</td>
<td>8 (13)</td>
<td>8 (50)</td>
<td>2 (2)</td>
</tr>
<tr>
<td>Patient Non-compliance</td>
<td>22 (36)</td>
<td>0 (0)</td>
<td>24 (31)</td>
</tr>
<tr>
<td>Cost of Obtaining Care</td>
<td>6 (10)</td>
<td>4 (25)</td>
<td>12 (16)</td>
</tr>
<tr>
<td>Uncontrolled IOP</td>
<td>2 (3)</td>
<td>2 (13)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Lack of Patient Education</td>
<td>5 (8)</td>
<td>0 (0)</td>
<td>6 (8)</td>
</tr>
<tr>
<td>Asymptomatic</td>
<td>6 (10)</td>
<td>0 (0)</td>
<td>9 (12)</td>
</tr>
<tr>
<td>Optic Neuropathy</td>
<td>2 (3)</td>
<td>0 (0)</td>
<td>0 (0)</td>
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<tr>
<td>Missed/Delayed Diagnosis</td>
<td>5 (8)</td>
<td>2 (13)</td>
<td>12 (16)</td>
</tr>
<tr>
<td>Provider Avoidance</td>
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<td>0 (0)</td>
<td>5 (6)</td>
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<tr>
<td>Lack of Referral</td>
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<td>0 (0)</td>
<td>3 (4)</td>
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<tr>
<td>No Available Cure</td>
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<td>0 (0)</td>
<td>2 (2)</td>
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<tr>
<td>Other More Serious Conditions</td>
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<td>2 (2)</td>
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<tr>
<td>IOP Poor Measure</td>
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<td>0 (0)</td>
<td>2 (2)</td>
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<tr>
<td>Total Comments</td>
<td>61</td>
<td>16</td>
<td>77</td>
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Table 3. Suggested Potential Areas of Intervention to Reduce Loss of Vision

<table>
<thead>
<tr>
<th>Potential Areas of Intervention Response Category</th>
<th>Group-Specific Responses n (%)</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Patients</td>
</tr>
<tr>
<td>Provider Honesty</td>
<td>3 (13)</td>
</tr>
<tr>
<td>Tighter Follow-up</td>
<td>6 (25)</td>
</tr>
<tr>
<td>Improve Patient Education</td>
<td>12 (50)</td>
</tr>
<tr>
<td>Provider Sensitivity/Interest</td>
<td>3 (13)</td>
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<tr>
<td>Family Education/Involvement</td>
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<tr>
<td>Improve Provider Education</td>
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<tr>
<td>Simplify Patient Literature</td>
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<tr>
<td>Improve Screening</td>
<td>0 (0)</td>
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<tr>
<td>Reduce Cost of Treatment</td>
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<tr>
<td>Increase Referrals</td>
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<tr>
<td>Increase Public Awareness</td>
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<tr>
<td>Use of Standardized Care</td>
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</tr>
<tr>
<td>Increased Appointment Time</td>
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</tbody>
</table>

**Total Comments** 24 14 40
Figure Legends

Figure 1. Percentage of response comments with respect to perceived causes of LOV for patient, family member or friend, and eye-care providers.

Figure 2. Percentage of response comments with respect to potential areas of intervention for patient, family member or friend, and eye-care providers.
**References**


Percentage of Response Comments

- Appointment Time
- Standardized Care
- Public Awareness
- Referrals
- Reduce Cost
- Screening
- Patient Literature
- Provider Education
- Family Education
- Provider Interest
- Patient Education
- Tighter Follow-up
- Provider Honesty

Legend:
- Eye-Care Providers
- Family Member/Caregiver
- Patients