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## Why Patients With Glaucoma Lose Vision: The Patient Perspective

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### Abstract

**Purpose**—To explore why glaucoma patients believe that glaucoma continues to cause vision loss despite the availability of effective treatment.

**Methods**—Nine focus groups were conducted in 3 geographically and ethnically diverse areas of the United States (Los Angeles, CA; Rochester, MN; Durham, NC) that included 56 participants, 31 with poor vision and 25 with good vision. Content analysis was used to identify important themes. Semi-quantitative analysis was used to measure the frequency of each theme.

**Results**—474 relevant comments were made in the nine focus groups. Focus groups elicited 305 comments about barriers to glaucoma management including issues with adherence (30%), the doctor-patient relationship (21%), knowledge about glaucoma (19%), personal support systems (19%), and barriers to healthcare delivery such as cost and insurance (11%). 101 comments were made regarding feelings about glaucoma and 58 comments were made regarding beliefs about disease and treatment.

**Conclusion**—These focus groups brought up many issues surrounding barriers to glaucoma treatment, perceived susceptibility to glaucoma, perceived benefits to treatment and the emotional response to living with glaucoma. There is a need to create a more comprehensive chronic disease management approach for patients with glaucoma to address both the concrete and emotional issues identified in these focus group discussions.

### Introduction

Despite the fairly high number of evidence-based treatments for glaucoma, it remains a leading cause of blindness in the United States. The prevalence of glaucoma is 1.9% among

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On-line material: Semi-Structured Interview Guide, Patient Focus Group, Appendix 1

the US population over the age of 40 and 7.9% among the US population over the age of 80. As the number of octogenarians in the US increases, glaucoma will become a more pressing public health issue.

There are many potential reasons why glaucoma remains a disease that is so difficult to arrest on a population level. As an initially asymptomatic disease, patients are unlikely to seek out evaluation themselves and the US Preventive Task Force has stated that eye care providers do not currently have an effective way to screen the population for glaucoma. Once a patient is diagnosed with glaucoma, we know from a systematic review of 29 studies that up to 80% of glaucoma patients do not adhere to treatment recommendations. Poor adherence to medications is a multifactorial issue, and previous studies have identified many barriers to glaucoma medication adherence including cost<sup>1</sup>; forgetfulness<sup>2</sup>; side effects<sup>3</sup>; difficulty instilling eye drops<sup>4</sup>; skepticism that glaucoma will cause vision loss<sup>5</sup>; skepticism that glaucoma medications are effective<sup>6</sup>; a lack of knowledge about glaucoma<sup>7</sup>; a lack of self-efficacy<sup>8</sup>; difficulties with the medication schedule<sup>9</sup>; a poor doctor patient relationship; and perceived life stress. Ung and colleagues found that those with less severe disease were less adherent to their medications, while those with more severe disease were less adherent with their follow-up care, indicating that there may be different issues that face glaucoma patients early and later in their disease process.

The objective of this study was to explore why glaucoma patients believe that glaucoma continues to cause blindness, including exploring patient's perceived barriers to effective treatment. Focus groups were conducted with glaucoma patients with good vision and glaucoma patients with poor vision in order to compare these different perspectives on barriers to optimal glaucoma treatment.

## Methods

### Focus Group Subjects

Participants in focus groups were selected to maintain homogeneity in critical characteristics to ensure that adequate discussion would occur. Groups were allocated by the following criteria: 1) patients with vision of at least 20/40 vision in both eyes and AGIS score on visual fields of 6 or less in the worse eye ("good" vision); 2) family members or friends of those with good vision; 3) patients who were legally blind in at least one eye, with vision worse than 20/200 OR a visual field of 10 degrees or less ("poor" vision) and 4) family members or friends of those with poor vision. Care was taken with the patient and family groups to have groups that were of both higher and lower socio-economic status.

### Creating the Focus Group Interview Guide

Semi-structured interviews and focus groups were performed in 3 geographically and ethnically diverse areas of the United States – Los Angeles, CA, Rochester, MN, and Durham, NC. Each site used a standardized study protocol overseen by the PI (PPL) and site PIs (AC, Los Angeles, CA; DJ, Rochester, MN; LH, Durham NC). All study interviewers and focus group moderators underwent a standardized training regimen. Research staff conducting the interviews and focus groups with patients were not involved in patient care.

Overall, the study specifically sought input from patients with glaucoma (both those with vision loss and those without), family members and friends of those with glaucoma, and community or front-line providers of care for patients with glaucoma.

A total of 12 structured interviews were carried out at the 3 sites (4 per site) with the following key stakeholders: 3 for patients with good vision, 3 for patients with poor vision, and 6 for family members of both types of patients (3 with good vision, 3 with poor vision). The interview guide was created based on an extensive literature review. The results of the literature review and interviews were then used to create one focus group script for the patient focus group and one interview script for the support system focus group. These semi-structured interview guides underwent pilot testing and additional revision (Semi-Structured Interview Guide, Patient Focus Group Appendix 1, available on-line only).

### **Patient Focus Groups**

A total of nine focus groups were conducted with patients who had glaucoma. These included four patient groups with good vision and five patient groups with poor vision. Each focus group had between 5–7 subjects for a total of 56 participants. All focus groups were audio- and/or video- taped. Transcripts were then created using the tapes and written notes of each session. Each site PI reviewed the transcripts and made any necessary corrections based on the written contemporaneous notes taken by study personnel at the time the group was being conducted.

Content analyses were then conducted on the data collected in the focus groups. The transcripts were coded for themes independently by two reviewers (PANC, RS). The reviewers came to a consensus on how to classify the identified themes and created a codebook with the definition of each theme. The two reviewers then re-coded each transcript using the codebook. Statements that were classified differently were discussed until consensus was reached. The entire study team agreed on the thematic interpretation of the transcripts. In order to understand the potential factors of interest that were raised in the focus group discussions, we both identify whether a stated factor was mentioned in the focus groups and how frequently it was mentioned. Although our primary purpose was to identify the range of issues facing glaucoma patients with good vision and those with poor vision, we also included semi-quantitative analysis of the frequency with which concept domains were raised and addressed in these focus group discussions.

### **IRB**

This study received Institutional Review Board approval at each institution in which it was conducted and adhered to the tenets of the Declaration of Helsinki.

## **Results**

### **Description of the Subject Population and Focus Groups**

Of the 56 focus group participants, 31 participants had poor vision and 25 had good vision. Of those who had poor vision, 16 (52%) were men and 15 (48%) were women. Of those who had good vision, 14 (56%) were men and 11(44%) were women. The age ranges in the

good vision focus groups were 43–90 and those in the poor vision focus groups were 49–86. All comments made in the focus groups that were relevant to the primary study question, why glaucoma continues to cause blindness, were extracted and coded. There were a total of 474 relevant comments from the nine focus groups with a range of 7–71 relevant comments made in each focus group. Four main themes arose in the content analysis of the focus group transcripts: beliefs about glaucoma and its treatment, barriers to controlling glaucoma, issues with adherence and the emotional burden of having glaucoma.

### **Beliefs about Disease and Treatment**

People conceptualize their illnesses and the treatment for their disease in different ways. They do not always think about their illness, or in this case, their glaucoma, in a strictly patho-physiologic way. People have their own perceptions of both disease-related and treatment-related symptoms and they construct their own mental model about what glaucoma is and how glaucoma affects their life. Overall, there were 58 distinct comments made regarding beliefs about glaucoma (25 comments made by 17 subjects) and its treatment (33 comments made by 23 subjects) (Table 1). An important theme that arose was that of the asymptomatic nature of glaucoma, reflected in comments such as glaucoma is “not a very visible thing and it’s really easy to ignore.” Both those who had poor vision and those who had good vision reflected the sentiment that it is easy not to prioritize glaucoma when it is not “bothering you.” There was an overall belief that once people were prescribed appropriate treatment, the treatment was effective in preventing vision loss. This belief gave people a sense of control over the disease; “[i]n my case, taking the drops is the control.”

### **Barriers to Controlling Glaucoma**

Not including issues with adherence, there were 222 distinct comments made regarding barriers to optimally managing glaucoma, and results are described in Table 2. The frequency with which comments were made were as follows: 1) 67 comments were made about the doctor-patient relationship (32 people); 2) 60 comments were made about glaucoma knowledge (40 people); 3) 59 comments were made about support systems (34 people); 4) 36 comments were made about systems barriers (19 people) (Table 2). The most prevalent issue was the doctor-patient relationship, and the focus of the doctor-patient relationship for many patients was how much time the patient perceived the physician spent with them, and that was mainly determined by whether the patient felt like the doctor elicited and listened to their concerns and then provided adequate responses. For example, “[t]he doctor has to ask the questions and draw it out of the patient, and that takes time and some doctors either don’t have the time or don’t take the time”(Table 2).

The second most common barrier was knowledge about glaucoma, and there were two different types of learning preferences that emerged. One set of participants (29/60 [48%] comments) preferred to learn all they needed to know about glaucoma through their doctor, “I just leave it up to the doctor... he knows best I think.” Another set of participants (31/60 [52%] comments) preferred to learn about glaucoma through multiple sources, and would go out of their way to find new sources of information about glaucoma, “anything in a magazine or a newspaper that has glaucoma in it, I read it.”

The third type of barrier discussed was support systems. The types of comments made about support systems varied by type of support (positive vs negative) and gender. Overall, 46/59 (78%) comments described positive support systems and 13/59 (22%) comments described negative support or a lack of support. Among the men, 32/33 (97%) comments described positive family support while among women, only 14/26 (54%) comments described positive family support. For example, a male participant stated “[m]y wife constantly says ‘have you put your drop in,’ she knows I do it but she still has got to ask” in contrast to a female participant who stated “[b]ecause nothing is visible, I don’t think it dawns on my husband, he knows I have trouble seeing and he still just forges on you know and I’m stumbling along behind him.”

The least frequently mentioned obstacle was systems barriers. The majority of the comments made about systems barriers had to do with financial issues with cost and insurance companies. Subjects reported difficulties obtaining authorization for services from insurance companies, issues maintaining or obtaining insurance coverage and issues getting coverage for their preferred provider.

Another interesting issue that arose was screening. 20 participants made 35 distinct comments about the need for improved screening for glaucoma in order to catch the disease in an earlier state, such as “[y]ou have to have a good screening system because there are an awful lot of people out there who have glaucoma and have no idea they do.” The discussion about the importance of screening for glaucoma as a public health issue appeared to stem from the feelings of remorse about being diagnosed at a later stage of disease. One participant noted “I wish I had been diagnosed earlier.”

### Adherence

There were 93 unique comments made about issues with medication adherence (Table 3). General comments (26 comments, 17 people) included ones like “I’ve tried to do everything I’m supposed to do because I worry.” Those who had poor vision contributed 65% (17/26) of the comments about adherence in general compared to 35% among those who had good vision (9/26). Interestingly, comments about adherence differed when participants were asked about what they would tell someone newly diagnosed with glaucoma about managing their disease as compared to the difficulties they themselves experienced when trying to be adherent to their medications. The type of comment that subjects made about taking care of their own glaucoma is well reflected in “[i]t is a very difficult disease to detect when you’ve got it or you don’t have it you’re not aware of it so...why do anything if nothing is bothering you I guess” as compared to the type of comment subjects made about what they would tell others to do if they were diagnosed with glaucoma: “[i]t is just very important that you use your drops and [do] whatever you are told to do.”

Difficulties with drop administration were relatively common (20 comments, 15 people), and many people reported issues with squeezing the bottle appropriately; “[w]hen you don’t squeeze, it doesn’t come out and when you do squeeze it, you get more than one drop. Consequently, the bottle doesn’t last as long as they advertise it lasting.” This was another issue which differed based on vision status, with 85% (17/20) of comments made by those who had good vision compared to 15% among those who had poor vision (3/20).

Side effects were another significant barrier (13 comments, 13 people), with comments like “[m]y eyes got redder and redder and I got more frustrated.” Less common issues were problems with the complexity of the medication schedule (10 comments, 10 people), problems with forgetfulness (5 comments, 5 people), and problems with cost (15 comments, 12 people). Four participants made comments about how they had generated systems to remind themselves to take their drops, or cues to action, such as: “I take a lot of other medicines so I put it out along with the medicine that I take before I go to bed.”

### Feelings about Glaucoma

There were 101 comments where participants were describing their feelings about glaucoma, and comments about feelings were made in all nine focus groups, and the results are described in Table 4. The types of feelings described did not differ much by vision status, as both those with poor vision and those with good vision reported emotions that ranged from fear to apathy to acceptance. An example of fear was “I knew what it was and I was scared to death.” The type of apathy present in the discussion was well represented by the quote “I was surprised but it didn’t bother me- it didn’t phase me. No one in my family has ever had it. I know very little about it so it really didn’t bother me.” There were also those who had made peace with their diagnosis and were able to manage it, “I decided that, well, it was something that could be taken care of so I wasn’t going to worry about it.”

Fear of blindness was an important theme that emerged as well. Fear of blindness was more commonly reported by those participants in the poor vision groups, where those with poor vision made 69% (11/16) of the comments about this fear. However, this fear was not limited to those whose vision was affected by glaucoma, as even a participant who still had good vision reported that “[w]ell, everybody I knew who has glaucoma eventually became blind, so I figured that was my fate too.” A third theme that participants commented on was a fear of loss of independence (14 comments, 11 people). The grand majority (93%, 13/14) of these comments were describing the fear of not being able to drive. Interestingly, the majority of the concerns about not being able to drive were brought up by those with good vision (77%, 10/13 comments).

### Discussion

The purpose of these focus groups was to elucidate why patients think that people with glaucoma lose vision even though effective treatments exist. Major themes that arose through these discussions included beliefs about glaucoma and its treatment and barriers to controlling glaucoma. Throughout the discussions, participants also mentioned their emotional responses to glaucoma including a fear of blindness and a fear of loss of independence.

The Health Belief Model is a theory of health behavior that was developed by public health officials in the 1950’s to explain why people did not participate in screening tests for asymptomatic diseases. The theory postulates that a specific health behavior, such as managing glaucoma in this case, is influenced by a person’s *perceived susceptibility* to the disease, the *perceived severity* of the disease, the *perceived benefits to treatment* and the *perceived barriers* to the recommended behavior change. For a glaucoma patient, this would

mean that the person would only take their medication and return for their follow-up appointments if they believed that glaucoma would cause undesirable vision loss, the treatments offered by their doctor could mitigate this effect, and the barriers to following their physician's recommendation were not so difficult to overcome that they outweighed the perceived benefit of treatment. The Health Belief Model also discusses that *cues to action*, or stimuli that could trigger the desired behavior, could help people overcome their barriers and carry out the desired health behavior. The type of cues to action involve ideas like integrating taking glaucoma medications into the daily routine, such as by linking taking a prostaglandin analogue to taking additional oral medications before bed.

These focus groups brought up many issues surrounding glaucoma patients' perceived susceptibility to and perceived severity of the disease as well as the perceived benefits to treatment. An issue that participants acknowledged many times was the asymptomatic nature of glaucoma. One participant stated: "[t]hat's the problem with glaucoma, there is no way of knowing you have that until you do have a check-up. In fact there is no pain or nothing with it until it's too late." Once subjects truly accepted the fact that they had a chronic disease that can become very severe, they were able to give more weight to the benefits of treatment. Another participant said "[i]t really scared me for a while until I realized that if I treated it and the treatment worked, I didn't, I shouldn't say didn't have to worry about that, but at least I could slow it down considerably."

Focus group participants brought up many barriers to optimal glaucoma management. The barriers included issues with adherence (30%, 93/315 of comments about barriers), the doctor-patient relationship (21%, 67/315), knowledge about glaucoma (19%, 60/315), personal support systems (19%, 59/315) and overarching health care delivery system barriers (11%, 36/315). Issues with adherence are inextricably linked to both the other categories of barriers that participants mentioned as well as to beliefs about glaucoma and its treatment. If patients do not believe that glaucoma will affect them because they have not noticed any change in their vision, do not have a good, trusting relationship with their eye care provider, do not understand the chronic nature of glaucoma, do not have a good support system at home, or cannot afford management and treatment for their glaucoma, it is very likely that patients with any of these important barriers will be poorly adherent to their treatment regimen. Poor adherence to glaucoma medications and follow-up visits is associated with more advanced glaucomatous disease<sup>17</sup>.

This study had a number of limitations. The focus group moderators were different at each site. Though they each underwent the same training, they each had different levels of experience and each facilitated the conversation in a slightly different way. This study was also undertaken at tertiary care academic medical centers where many of the patients were cared for by glaucoma specialists who served as investigators in this study. This could have biased the comments in the focus groups as patients may not have been comfortable making negative statements about the care received from their current care providers even though the moderators stated that the research would not affect clinical care. Though patients represented a broad range of ages (43–90), we did not purposefully sample to ensure that a certain percentage of participants were older (>75 years old), so we cannot comment on how aging might affect the themes generated. The content of the focus groups was mainly



analyzed by glaucoma specialists and by a cornea specialist (SM). Subspecialists may bring a different lens to the analysis than comprehensive ophthalmologists or behavioral psychologists.

While the Health Belief Model addresses many of the themes that glaucoma patients mentioned in our focus groups, it does not discuss how people's emotions might impact these different constructs, and we found that glaucoma patients wanted to discuss their emotional reaction to their diagnosis and management of their glaucoma. We need to create a space within the delivery of ophthalmic care to address patients' emotional needs surrounding managing their glaucoma. With the projected growth in the number of glaucoma patients as the population ages and the concomitant projected workforce issues for ophthalmologists relative to increased demand, physicians will not be able to provide all of the necessary emotional support for their patients with chronic disease. Paraprofessional staff will need to become key players in providing counseling and education for glaucoma patients to help them cope with the emotional burden of living with glaucoma. There are excellent examples for how paraprofessional staff can educate patients and aid in their disease self-management in chronic diseases in internal medicine such as hypertension and diabetes<sup>7</sup>. There is a need to create similar paradigms in ophthalmology to aid our patients in improving their chronic disease self-management. This type of a paradigm for providing support for disease self-management for our glaucoma patients may help address some of the reasons that patients continue to lose vision from glaucoma, despite the availability of effective medical treatment.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**Table 1**

Disease and Treatment Beliefs

Category	Good vision Number of Comments	Number of People	Number of Focus Groups	Example Quotes	Poor Vision Number of Comments	Number of People	Number of Focus Groups	Example Quotes
Disease Beliefs	15	8	3	“It is very difficult disease to detect when you’ve got it or you don’t have it if you’re not aware of it ... why do anything if nothing is bothering you I guess.”	10	9	4	“It’s not a very visible thing and its really easy to ignore.”
Treatment Beliefs	16	13	5	“It’s not the end of the world. It’s like diabetes, you can take insulin and in this case we take drops and so if you’re diligent in what you’re doing, I think you’ll keep your eyesight.”	17	10	4	“In my case, taking the drops is the control.”

Table 2

## Barriers to Controlling Glaucoma

Category	Good Vision Number of Comments	Number of People	Number of Focus Groups	Example Quotes	Poor Vision Number of Comments	Number of People	Number of Focus Groups	Example Quotes
<b>Adherence</b>	See table 3							
<b>Dr/Pt Relationship</b>	25	15	5	"The doctor has to ask the questions and draw it out of the patient, and that takes time and some doctors either don't have the time or don't take the time."	42	17	5	"Dr. Johnson is a person that will listen to the patient."
<b>Systems Barriers</b>	17	9	4	"We fought for a year and a half with the insurance company for them to give me the okay for me to have the preventive surgery and Dr. Johnson finally ended up writing a nasty letters to the insurance and they decided to let me do it."	19	10	3	"People have to pay for their visits to the doctor every time they go and then pay for this drop that doesn't work, then we'll try that drop, it gets to be either eat or ... it's hard to realize that when you're well covered with insurance but if you are not it's murder."
<b>Knowledge</b>	31	18	4		29	22	5	
	17 (Doctor's)	14	4	"I don't think it's necessary that I be super well-informed about glaucoma. I am trusting that my doctor at the Mayo Clinic will be very well informed. I trust him."	12 (Doctor's)	9	4	"I just leave it up to the doctor. He knows best I think."
	14 (Patient's)	10	4	"Anything in a magazine or newspaper that has glaucoma in it, I read it."	17	14	5	"I try to read whatever I see. Any material about glaucoma and also they have it in TV sometimes."
<b>Support</b>	29	16	4		30	18	4	
	Male: 14			N: "My wife has far more serious eye problems so this is second fiddle. She has macular degeneration." P: "My wife constantly says, 'have you put your drop in?' She knows I do it but she still has got to ask."	Male: 19			N: "Most of my family except my wife probably don't even understand about it. She understands because she always comes to the doctors with me and when he explains it to me ..." P: "My wife is my primary caretaker and my children

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Category	Good Vision Number of Comments	Number of People	Number of Focus Groups	Example Quotes	Poor Vision Number of Comments	Number of People	Number of Focus Groups	Example Quotes
	Female: 15			<p>P: "My family is very interested. If I need a ride or something like that, they're there."                      N: "My family is concerned, but they are too far away to do or be of any help really."</p>	Female: 11			<p>P: "I hang onto Jack when I can't see too well, and we walk together."                      N: "Because there is nothing visible, I don't think that it dawns on my husband. He knows I have trouble seeing and he still just forgets, you know, and I'm stumbling along behind him."</p>

**Table 3**

Adherence Issues

Category	Good Vision Number of Comments	Number of People	Number of Focus Groups	Example Quotes	Poor Vision Number of Comments	Number of People	Number of Focus Groups	Example Quotes
<b>Adherence (general)</b>	9	8	3	"I do what the doctors tell me to – I'm really good at following instructions, try to be."	17	9	5	"I've tried to do everything that I'm supposed to do because I worry."
<b>Medication schedule</b>	7	4	2	"The problem was me taking a lot of them two or three different drops two or three different times a day a day again it was very hard to remember the right schedule first of all."	3	3	2	"So how do you keep them straight?"
<b>Drop administration</b>	17	12	3	"When you don't squeeze it doesn't come out and when you do squeeze it you get more than one drop. Consequently the bottle doesn't last as long as they advertise it lasting."	3	3	2	"My husband helps me ... I have ointment that I have to put in the eye and I have trouble getting that in ... I don't want to waste any of it's so darn expensive otherwise I can manage it myself."
<b>Side effects</b>	10	7	3	"After I use that my vision is fuzzy for an hour or so."	3	3	2	"My eyes get redder and redder and I got more frustrated."
<b>Forgetfulness</b>	4	4	3	"I think the biggest thing is being diligent I had to learn that. It didn't come to me easy and it's only been in the last probably 10 years that I've been really diligent with my eye drops."	1	1	1	"I've done everything I can ... if we are going away I take my drops with me. I have hardly ever missed a time."
<b>Cue to action</b>	3	3	1	"I take a lot of other medications so I put it out along with the medicine that I take before I go to bed."	1	1	1	"I remember having all my drops lined up and thank God they're different colored lids because I would initial each one and write them down whether you took them or not...carry them around with me when I went anywhere."

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Category	Good Vision	Number of Comments	Number of People	Number of Focus Groups	Example Quotes	Poor Vision	Number of Comments	Number of People	Number of Focus Groups	Example Quotes
Cost	5	4	3	“That’s what, fifteen dollars running down there [my cheek].”	10	8	4	“Those little bottles at \$80 you don’t want to waste too many...”		



Table 4

## Feelings

Category	Good Vision Number of Comments	Number of People	Number of Focus Groups	Example Quotes	Poor Vision Number of Comments	Number of People	Number of Focus Groups	Example Quotes
<b>Feelings</b>	37	20	4	N: "Fright ... I had no symptoms" P: "I decided that well it was something that could be taken care of so I wasn't going to worry about it." A: "I was surprised but it didn't bother me – it didn't phase me. No one in my family has ever had it. I know very little about it so it really didn't bother me."	34	18	5	N: "I knew what it was and I was scared to death." P: "I guess I've pretty much learned to live with it."
<b>Fear of Blindness</b>	5	4	2	"Well everybody I knew who has glaucoma eventually became blind so I figured that was my fate too."	11	10	4	"I was confused. I didn't know what to think. I was afraid I would go blind."
<b>Fear of Loss of Independence</b>	10	7	4	"It used to be real hush-hush disease. You don't want anybody to know you had eye problem because they correlate not seeing well with eye problems and they think if you don't see well they think you shouldn't be out there driving."	4	4	4	"The thing that scares me more than anything is that I'm still driving and I want to keep my independence. I want to keep driving and doing everything I do and I think the day will come so when I become blind I'll hire a driver ..."

N, Negative feeling; P, Positive feeling; A, Apathetic feeling