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# Barriers To Eye Care Among Patients With Age-Related Macular Degeneration In The Yale Eye Center

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# BARRIERS TO EYE CARE AMONG PATIENTS WITH AGE-RELATED MACULAR DEGENERATION IN THE YALE EYE CENTER

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## ABSTRACT

BARRIERS TO EYE CARE AMONG PATIENTS WITH AGE-RELATED MACULAR DEGENERATION IN THE YALE EYE CENTER. Laura B. Hall and Ron A. Adelman. Department of Ophthalmology and Visual Science. Yale University, School of Medicine, New Haven, CT.

Barriers to obtaining medical care have been studied extensively across the health care realm. Within ophthalmology barriers to receiving care for cataracts and diabetic retinopathy (DR) have been considered. To the best of our knowledge, the barriers to receiving care for those suffering from age-related macular degeneration (AMD) in the United States have not been explicitly studied. AMD is a disease that disproportionally affects the elderly and when left untreated will often cause legal blindness. Early detection and treatment is essential to avert AMD progression. Studying the way in which patients receive their eye care and what barriers or enabling factors they may experience when receiving this care is crucial.

We hypothesize that barriers to care for patients with age-related macular degeneration are necessarily distinct from those barriers already identified affecting patients with diabetic retinopathy as the patient population is necessarily distinct. This study aims to: 1) to assess patient's understanding of age-related macular degeneration and its disease types, treatment options, and long-term sequelae; 2) to elicit patient's views on and concerns about their eye care; 3) to ascertain the most frequently perceived barriers and enabling factors to seeking care amongst patients with age-related macular degeneration at the Yale Eye Center; and 4) to develop a questionnaire using the information gained from aims 1-3 that can be self-administered by Yale Eye Center age-related macular degeneration and diabetic retinopathy patients.

To accomplish this goal a qualitative approach was taken consisting of semi-structured interviews conducted with Yale Eye Center (YEC) patients with AMD and DR. All interviews were transcribed and coded to identify emerging themes.

We found that patients with age-related macular degeneration have some similar and some unique barriers as compared to patients with diabetic retinopathy. Major deterrents include: 1) confusion and limited knowledge of AMD, 2) access to specialist care, 3) financial constraints, 4) difficulty buying and locating, and unsure of indications for taking, AREDS2, 5) frequency and length of clinic visits, and 6) fear of requiring an intravitreal injection. The key enabling factors that motivated patients to seek care are their positive attitudes about vision and eye care and confidence in their providers.

With the knowledge gained from these semi-structured interviews, physicians can direct their attention to these focal issues in order to provide the best and most effective patient care. A formal questionnaire was developed using the insight gained from these interviews and this will provide large-scale standardized data to make further generalizations in the field.

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**TABLE OF CONTENTS**

## I. INTRODUCTION

Barriers to obtaining medical care have been studied extensively across the health care realm. The current literature pays special attention to vulnerable populations including children, minorities and those with disabilities, and to those with chronic conditions such as hypertension, heart disease, diabetes and stroke. (1-3)

Age-related macular degeneration (AMD) is a disease that disproportionally affects the elderly and when left untreated will often cause legal blindness. Estimates in 2010 were that it affected nearly 24 million people and that in 2050 it could impact up to 80 million. (4) In the developed world AMD is the number one cause of irreversible blindness for those greater than 50 and in the US alone it affects approximately 10 million elderly. Those ≥ 75 years of age have an 8.7% prevalence of ever being diagnosed with the condition. (5)

Early detection and treatment has proven helpful in slowing or averting AMD progression to more advanced, deleterious forms of disease. (6, 7) Consequently, studying the way in which patients receive their eye care and what barriers they may experience when receiving this care is crucial. To the best of our knowledge, the barriers to receiving care for those suffering from AMD in the United States have not been explicitly studied.

The recent introduction of anti-VEGF injections and the use of AREDS2 vitamins have revolutionized AMD treatment and prognosis. (8-10) Therefore, ensuring that patients get treatment quickly and effectively may prevent them from developing what is often now considered preventable vision loss. Understanding and addressing the barriers to the patient care experience is the first step.

Within the field of ophthalmology many studies have assessed barriers to receiving care for cataracts (11, 12) and diabetic retinopathy. (13-16) While these are two of the most common ophthalmologic complaints, as outlined above age-related macular degeneration is also quite prevalent and debilitating. Accordingly, what is of particular interest is that to date there have been no studies that have assessed barriers to care for the United States population with AMD.

While there are currently no known studies directly addressing barriers to accessing care in the United States for those with AMD, there have been a handful of studies on this general topic conducted in other countries. A Pubmed search completed in January 2013 using the search terms “age-related macular degeneration” and/or “AMD” and “barriers to care” and/or “access to care” yielded no relevant results. Using the simple search term “barriers” and/or “access” yielded 44 and 70 articles respectively. All abstracts were reviewed and only a few articles were applicable. The most striking was a May 2012 study from Germany entitled *“Access to healthcare services for elderly patients with neovascular age-related macular degeneration”* [Versorgung von älteren Menschen mit neovaskulärer altersabhängiger Makuladegeneration]. (17) It concludes “fewer elderly persons and in particular elderly women seemed to access treatment for [neovascular]-AMD than expected. Future studies should investigate barriers in accessing treatment for nv-AMD and how to address these problems.” This paper is not available in English, despite requests to the author, and it has not been formally translated. Pubmed reported 71 “related” articles to this one of interest. All of those abstracts were reviewed and none addressed barriers to care explicitly. This German paper has been cited only once since its publication and it was in a study on the safety of anti-VEGF injections. (18)

Somewhat touching on the subject was a 2010 study from the US Centers for Disease Control (CDC) of women over 40 years of age that assessed eye care utilization. Overall, it found that women without insurance coverage for eye-care or those who did not receive routine medical check-ups were more likely to report not having the recommended follow-up eye-care. Of those women in the study with self-reported AMD, 8% did not visit an eye-care provider in the recommended follow-up period. (19) Yet this CDC report did not extensively study the barriers to care in AMD. Furthermore, Medicare covers many of the patients affected by AMD so the issue of being without insurance coverage is not as applicable to the study patient population.

Another article that commented on the topic was a Canadian policy review entitled "The treatment of wet AMD in Canada: access to therapy (policy review)" and it focused more on the intricacies of the Canadian reimbursement and medication coverage system. (20) These were the only three applicable articles found at that time of this study proposal.

A query on Pubmed in January 2014 found a qualitative study using 2010 data from the UK entitled "' I'd like to know what causes it, you know, anything I've done?' Are we meeting the information and support needs of patients with macular degeneration? A qualitative study." (21) This article highlighted that patients have information deficits in knowledge of their disease (ranging from diagnostic questions, to cause, treatment and prognosis) but did not specifically address barriers to receiving eye care.

A recent search on the World Wide Web yielded a new consortium piece worth mentioning. The report is based on the Australian Wet AMD Coalition Expert Summit and was sponsored by The Angiogenesis Foundation. It produced a white paper in May

2013 entitled "Advocating for Improved Treatment and Outcomes for Wet Age-Related Macular Degeneration" and is the first source we found to distinctly list barriers to receiving AMD care. It classified them according to barriers 1) related to patients, families and caregivers, 2) related to health care professionals and institutions, and 3) related to government policies and services. It simply listed barriers and did not go into detail. Further, while it was addressing the concerns of Australian AMD patients many of the overarching principles can be reflected on the United States health care arena and were illuminated in our research results. (22)

With the ever-changing healthcare environment and the introduction of newer, and perhaps more costly, anti-VEGF agents, relevant studies on barriers to care must be completed and analyzed. Owing to the lack of available information on the topic, we set out to identify the barriers to care in age-related macular degeneration for patients in the US.

The first step in addressing barriers to care is to identify them and that is where this study begins. Barriers to care are broad. They include processes that (1) interfere with a patient's positive interaction with the health care system and (2) reduce the likelihood of timely access, productive interactions, and positive outcomes.(1) Below is a summary of six overarching barriers compiled from many large studies, with particular focus on established barriers to care in diabetic retinopathy (DR). Diabetic retinopathy was chosen because it is also treated by ophthalmologists (in particular the same retinal specialists who treat AMD), requires close observation and routine dilated fundus examinations, and often requires similar imaging (OCT) and treatment (intravitreal injections and previously laser) techniques. Those affected most by age-related macular degeneration and diabetic

retinopathy have different epidemiologic backgrounds. This is seen anecdotally at the Yale Eye Center and in the literature. The former mainly affects elderly, white females (who are subsequently covered by Medicare) while the latter tends to affect middle-aged, black and Hispanics without a sex predilection. (4, 23) The predominant barriers found in the literature for diabetics with eye disease are below. Where appropriate, comparisons to potential barriers for AMD were made:

1) **Inadequate knowledge of disease severity and consequences**: Frequent studies have shown that lack of awareness and limited knowledge of disease severity and consequences are some of the greatest barriers to successful patient outcomes. (21) For example, patients are often aware that diabetes could affect the eye but not that it would lead to blindness, nor that severe retinopathy could be asymptomatic. (24, 25) Further, many studies have shown that these diabetic patients did not know that they required regular screening and monitoring by dilated eye exams. (13) Early AMD may also be asymptomatic and this may lead to late diagnoses. It is also important to note the relative greater prevalence of diabetes in the population as compared to the more rare AMD; thus one would assume that patients would have more general knowledge of diabetes as a disease entity and its pertinent complications than with AMD.

2) **Lack of adequate referrals or access to specialists**: In order to diagnose and treat any retinal disease, a skilled ophthalmologist must first perform a dilated fundus exam. Physician-related examples relating to this barrier may be the absence of the primary care providers' recommendation for the patient to see an ophthalmologist or a physician not versed in retinal exams who may miss the initial symptoms. Patient-

related examples are that the patient may fail to make a secondary follow-up eye appointment and/or they may have difficulty finding a retina specialist in their region. They may also have transportation issues hindering their visit to the ophthalmologist or may not be able to sacrifice time from away from work (and the loss in income) to visit the physician. All of these issues have been cited as common reasons why diabetic eye disease escalates unnecessarily. (13, 26)

3) **Financial constraints:** Financial matters such as income, employment and insurance status typically influence access and use of health care services. Many previous studies of barriers to receiving ophthalmologic care have been conducted in Europe and Canada where there is national healthcare coverage and the US insurance market is on the verge of drastic changes. Diabetic patients tend to be younger than AMD patients and are more often without insurance, while Medicare generally covers most necessary diagnostic tools and treatment modalities for AMD patients. Of note, secondary insurance is often needed to cover the newer treatment modalities – specifically, newer anti-VEGF agents but it is costly to purchase these secondary policies. (13, 17)

4) **The fear of pain:** Patients are often wary of procedures involving manipulation of their eyes, particularly those involving lasers or injections. Both diabetic retinopathy and wet AMD require intrusive procedures and many consider them to be a very painful experience. (27, 28) In a head-to-head comparison of pan-retinal photocoagulation (a special laser used only for diabetic retinopathy also known as PRP) and intravitreal injections, the PRP was considered to cause much more discomfort than the injections. (28)

5) **The fear of going blind:** Such fear may contribute to patients' failure to make or a tendency to miss ophthalmologic appointments. Of course fear of losing vision may also act as an incentive for some to attend the eye clinic, but fear of being given a diagnosis of impending blindness can be a powerful disincentive. (24)

6) **Feelings of anxiety and guilt:** Patients often feel guilty about poor control of their health and diabetic symptoms. This leads them to not want to confront the physician about their condition. Type II diabetes is more often thought of as a "preventable" disease in that lifestyle choices (e.g. diet and exercise) strongly lead to the development, progression and/or regression of the disease. In contrast, AMD has fewer modifiable risk factors, i.e., one cannot stop the aging process and that is the strongest risk factor for its development and progression. However, more recently it was shown that the most consistent modifiable risk factor for AMD is smoking, though increased BMI, history of cardiovascular disease and hypertensive status have mild associations. (4) As such, patients have much less control over whether they develop AMD (and how advanced it becomes) than they do with type II diabetes.

Other barriers such as lacking skills to negotiate the health system, previous negative health experiences, logistical (e.g., transportation, taking time off from work, clinic hours), and feelings of marginalization greatly affect patients (and their caregivers) and must also be considered and examined.

Lastly, studies have shown that AMD strongly affects patients' quality of life (QoL). The MacDQoL is an individualized measure of the impact of AMD and other macular diseases on quality of life. It demonstrates that (1) AMD has a negative impact on quality

of life and (2) that there is a correlation between degree of visual impairment and impact of AMD on quality of life. (29) These are further reasons as to why it is essential to understand the barriers to receiving care and treatment for the growing elderly population in the USA.

Using the aforementioned general information on barriers to care in patients with diabetic retinopathy we set out to develop a qualitative analysis of barriers to care for patients suffering from age-related macular degeneration.

The Yale Eye Center is located in the heart of New Haven, Connecticut and attracts patients from across the state of Connecticut and Southern New England to receive eye care. These patients are likely a good representation of the population at large as the eye center accepts all types of insurance, including Medicare and Medicaid, and is the major referral center for eye physicians across the state. The goal of this study is to identify the perceived barriers to eye care and evaluate the concerns about vision and eye care among patients with age-related macular degeneration at the Yale Eye Center.

## **II. STATEMENT OF PURPOSE:** *Specific Hypothesis and Specific Aims*

We hypothesize that barriers to care for patients with age-related macular degeneration are necessarily distinct from those barriers affecting patients with diabetic retinopathy as the patient population is necessarily distinct. These barriers may prevent patients from seeking and obtaining adequate care, and understanding and defining such impediments is fundamentally important in improving patient health and population outcomes.

The specific aims of this study are: 1) to assess patient's understanding of age-related macular degeneration and its disease types, treatment options, and long-term sequelae; 2) to elicit patient's views on and concerns about their eye care; 3) to ascertain the most frequently perceived barriers and enabling factors to seeking care amongst patients with age-related macular degeneration at the Yale Eye Center; and 4) to develop a questionnaire using the information gained from aims 1-3 that can be self-administered by Yale Eye Center age-related macular degeneration and diabetic retinopathy patients.

## III. METHODS

### *Study Design*

A mixed-methods approach was taken to ascertain the perceived barriers patients with AMD experience when receiving eye care. To identify the specific aims we completed a qualitative study primarily using individual interview methods. A flexible qualitative approach was taken; this was because we were concerned with understanding the social, psychological and economical phenomena from the perspective of the study participants and the institutional context in which they occur. As there is little primary research on this topic, this methodology allowed us to investigate root causes and explore unexpected factors influencing these Yale Eye Center patients. This research framework used Martin and Turner's grounded theory where we gathered data based on the study participants' point of view and utilized an iterative analytical process where data analysis occurred throughout in order to generate more avenues of exploration. (30) A semi-structured interview style also allowed us to gain insight into specific geographic influence and reduce any preconceived bias and judgments.

### *Study Participants*

The Yale Eye Center is the clinical home to the Yale School of Medicine's and the Yale-New Haven Hospital's Department of Ophthalmology and Visual Science. In 2013 alone 29,000 outpatient clinic visits occurred in the department. It is a tertiary referral center and serves not only the population of the greater New Haven area but the entire southern New England area. In particular, the research mentor's retina clinic draws

approximately 2,700 outpatient visits every year and subjects were chosen from this patient pool. The student investigator had been assisting in this clinic for four months prior to the start of data collection and was thus immersed in the daily activities at the study location and observed the subjects within the institutional context. Effort was made to recruit as diverse a patient sample of possible with attention to gender, age, education level, insurance type and ethnicity. We recruited patients from March to May 2013 with AMD and from December 2013 to January 2014 with DR to use as a comparison population (Table A). The subjects were not new patients to the clinic; the physician had seen all at least once. Further, the patients had no other retinal diagnoses besides the condition of interest. The patients with age-related macular degeneration all had "active" disease meaning that if they had a diagnosis of dry AMD they were recommended to take "AREDS2" and if they had a diagnosis of wet AMD they were receiving anti-VEGF intravitreal injections treatment. The patients with diabetic retinopathy had either moderate to very severe non-proliferative diabetic retinopathy or proliferative diabetic retinopathy with or without diabetic macular edema. When the student researcher was available to conduct interviews, every patient who appeared in clinic during these times and fit the aforementioned inclusion criteria was asked to participate. All patients provided verbal consent.

*Data Collection*

The student researcher (LBH) conducted all one-to-one in-depth semi-structured interviews. Recorded interviews ranged in length from 15-50 minutes. The discussions were based upon the six key barriers identified in the *Introduction* section of this study. These general topics were identified and pilot tested before an interview script was

crafted (Table B). This script was modified throughout to explore new themes and acted only as a guide: participants were allowed to direct the course of the discussion. Data collection then proceeded until no new themes emerged. Precisely, the sample size evolved with the course of the research and was determined when theoretical thematic saturation was reached. The interviews were digitally recorded and transcribed verbatim by LBH.

*Data Analysis*

Data analysis was guided by Braun and Clarke's six stages of thematic analysis: familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. (31) The student researcher first read through all transcripts to obtain a general view of the study participants' responses with respect to the *Specific Aims* (to assess patients' understanding of their condition, to elicit patients concerns about their eye care, and to ascertain perceived barriers and enabling factor to receiving eye care). The student researcher with the assistance of the research mentor then coded the transcripts in an inductive manner to define concepts that emerged from the data. These concepts were reviewed and themes were defined and refined to categorize the participants' responses.

*Statement of Student Contribution*

The overall research question was formulated initially during discussions with the research mentor (RAA), a practicing retinologist and clinician-scientist. The student investigator (LBH) then developed the research protocol, conducted the interviews and performed initial data analysis. With the help of RAA the data analysis was finalized and

LBH produced the completed report.

*Role of the Funding Sources and Institutional Approval*

The funding sources had no role in the design, analysis or reporting of this study and its findings. The Yale University Institutional Review Board (HIC/HSC) approved this research protocol (HIC #1303011670).

## IV. RESULTS

*Study Participants*

There were twenty in-depth interviews with AMD participants and 8 with diabetic retinopathy. Table A shows the demographics of all participants.

**Table A. Participant Characteristics**

| Eye Condition | Macular Degeneration | Diabetic Retinopathy |
|---|---|---|
| Total Sample | 20 | 8 |
| Mean Age | 76.7 (range 59-92) | 64 (range 39-82) |
| Gender | | |
| Male | 5 (25%) | 4 (50%) |
| Female | 15 (75%) | 4 (50%) |
| Race | | |
| Non-Hispanic white | 19 (95%) | 5 (62.5%) |
| Non-Hispanic black | 1 (5%) | 2 (25%) |
| Hispanic | 0 | 1 (12.5%) |
| Health Coverage | | |
| Medicare | 0 | 5 (62.5%) |
| Medicaid | 0 | 2 (25%) |
| Medicare Plus (Dual) | 11 (45%) | 0 |
| Medicare and YHP | 6 (30%) | 0 |
| Private Insurance | 3 (15%) | 1 (12.5%) |
| Uninsured | 0 | 0 |
| Employment status | | |
| Employed | 6 (30%) | 1 (12.5%) |
| Self-employed | 0 | 2 (25%) |
| Retired | 13 (65%) | 4 (50%) |
| Unemployed | 0 | 1 (12.5%) |
| Not in labor force | 1 (5%) | |
| Education level | | |
| High School or less | 8 (40%) | 4 (50%) |
| Associates Degree | 3 (15%) | 2 (25%) |
| College (4 years) | 6 (30%) | 1 (12.5%) |
| Masters or higher | 3 (15%) | 1 (12.5%) |
| Disease type | Dry AMD OU: 5 (25%)<br>1 of those with GA OU<br>Dry and Wet AMD: 8 (40%)<br>Wet AMD OU: 7 (35%) | Severe NPDR: 4 (50%)<br>PDR: 4 (50%)<br>Received –<br>PRP 4 (50%)<br>F/G 4 (50%)<br>IVA 5 (62.5%)<br>Mean A1c 7.2 (range 5.5-8.6) n=5 |
| BCVA | | |
| Better eye | 20/42 | 20/36 |
| Worse eye | 20/108 | 20/84 |

**Table A.** BCVA (Best correct visual acuity) presented as mean logMAR converted to mean snellen BCVA, F/G (focal/grid laser) NPDR (non-proliferative diabetic retinopathy), GA (geographic atrophy) IVA (intravitreal Avastin injection) OU (oculas uterque, both eyes) PDR (proliferative diabetic retinopathy), PRP (pan-retinal photocoagulation) YHP (Yale Health Plan)

*Interview Guide*

Topics that were discussed during the semi-structured interviews included the following overarching ideas listed in Table B. Not all of the questions were asked outright but the interviewer ensured that all of the following topics were covered during each patient interaction. The same interview guide was used for patients with age-related macular degeneration and diabetic retinopathy but questions were tailored to the disease of interest.

**Table B. Interview Topic Guide**

| |
|---|
| Tell me **what you know** about age-related macular degeneration (AMD) or diabetic retinopathy (DR). |
| Tell me about **your** AMD (DR).<br>What are your eye **symptoms?** |
| Does AMD (or DR) in general **require treatment**? Your AMD (DR)?<br>**What happens if you do not treat it?** |
| Do you know if there are **different types** of AMD (DR)?<br>What are they? What are the differences?<br>DR only: Do you know if you have proliferative (PDR) or non-proliferative (NPDR)? |
| What are your **concerns** regarding your AMD (DR)? What **motivates** you to **come to your appointments** |
| Do you **feel as if you understand your eye disease** better now than at diagnosis?<br>Do you **need more information** on your condition? |
| How did you **come to the Yale Eye Center's** Retina Clinic? By whom were you **referred**?<br>Were there any issues? What were you **fears** in coming to the Yale Eye Center? |
| Are or were their any **financial restraints that altered the care** you previously or currently receive? |
| Have you ever **missed or avoided** an appointment?<br>If so, why? **Fear of pain**, **transportation** issue, **communication** issues, **wait** time, **illness**, etc.? |
| AMD only: Do you **take PreserVision?**<br>If yes → any **problems buying or finding** it at the store?<br>Have you ever **not bought or taken it because** of the cost? Do you take it **everyday?** |

| |
|---|
| Is the **size** of the pill troublesome? Do you not take it because you take **too many pills?** |
| What **medication** are you on? **Before** and **now**?<br>Do you **want a different one**? Did you not get it because of **financial constraints?** |
| What was your **fear before you had your first** injection? What about **now?** |
| DR only: What is your **experience with the laser** and the **stress** of it?<br>What **does the laser do**? What does the **injection do**? |
| Do you feel as if coming to your appointments **is important for your health?** |
| Who **brings you** to your eye appointments? |
| What is **your expectation of the medical treatment** you receive at the Yale Eye Center?<br>Are you satisfied? |
| What is **your expectation of your communication** with your Yale Eye Center physician?<br>Are you satisfied? |
| What **can the medical profession and health care system do to reduce barriers** to receiving proper AMD (DR) care?<br>To make your experience better? Or to help with your AMD (DR)? |
| Do you have a **primary care doctor?**<br>Do you see him/her regularly? |

Table B. Interview Topic Guide Continued

*Sample Interview Responses*

Table C presents typical responses from the semi-structured interviews. Participants 1-20 are patients with age-related macular degeneration (their respective responses indicated with use of bullet •) and patients 21-28 are patients with diabetic retinopathy (responses indicated with use of bullet ○). General, and comparable, responses are grouped together and direct patient responses are indicated within "quotation marks". Often participants made very similar remarks and those are also grouped. After each response a semicolon is placed and the corresponding respondents' study ID number ranging from 1-20 for AMD and 21-28 for DR is given.

**Table C. Participant responses**

| | |
|---|---|
| Tell me **what you know** about age-related macular degeneration (AMD) or diabetic retinopathy (DR)? | • Do not know anything about it: 1, 6<br>• Do not know much about it: 2, 4, 8, 15<br>• Affects / causes lose of vision: 2, 4, 7, 8, 9, 10, 12, 15, 17, 18<br>• It is bad for you: 1, 5<br>• They are different types:<br>  • "There is wet and dry": 14<br>  • "Wet is worse and the dry is better": 16<br>• Different treatments:<br>  • "There is no real cure": 13<br>  • "You treat wet with injections and dry no treatment": 16<br>• Discussed Causes:<br>  • "My glaucoma affects it": 3<br>  • "I'm unsure what causes it but my theories include exposure to sun or the x-rays I got to my face to treat acne in my youth": 5<br>  • "The cause is unknown": 9<br>  • "There is a genetic cause": 13<br>• Wavy lines:<br>  • "You get wavy lines": 7<br>  • "You see wobbly lines": 14<br>• Black spot: "You see grayness and haziness": 14<br>• Age-related: 3, 9<br>• Affects back of eye: 12, 19<br>• Affects retina: 14, 16, 18<br>• Affects central vision: 9, 14, 16<br>  • "It is deteriorating vision in the macula, making a hole": 20<br>• Involves leakage / swelling / fluid**:**<br>  • "Get fluid at back of retina: 7 |

| | |
|---|---|
| | • "There is a breaking down of the choroid membrane and retinal layers": 9<br>• "You have bleeding and inflammation behind the eye": 11<br>• "There is swelling and bleeding in the back": 12<br>• "Blood leakage behind retina": 14<br>• "Leakage of blood": 19<br>• "The wet has the bleeding": 20<br>• Discussed a family member's experience: 2<br>• "Many of my aunts and uncles had it. They all went blind": 11<br>• "My grandmother went blind, so she likely had it": 13<br>• "My father had it. He went blind from it": 15<br>• "Mom went blind. She must have had it": 16<br><br>o Not too much: 21, 24<br>o Unsure cause:<br>o "Not sure what causes it": 26<br>o Affects vision: 22-26, 28<br>o Diabetes in the eye: 21-23<br>o "It's caused by overtime the sugars being way out of control. It's debilitating and worsens with high sugars": 27<br>o "Result of bad blood sugar control": 28<br>o Discussed treatments:<br>o "There are ways to treat it. You can get a needle in the eye or laser but it's really the control of blood sugars": 28<br>o Involves bleeding:<br>o "It's accumulation of blood in the eye": 22<br>o "Diabetes gets into the blood stream and makes the vessels weak and they leak blood": 23<br>o "It's blood cells that are open around the eye in the retina and cause a reduction in vision": 28<br>o Involves swelling: |

| | |
|---|---|
| | o "I get shots for the swelling": 24<br>o "It's swelling behind the eye and a leakage of fluid": 25 |
| Tell me about **your** AMD (DR). What are your eye symptoms? | • No symptoms:<br>• At diagnosis and currently: 2, 4, 6<br>• At diagnosis: 8, 11, 15, 16, 18<br>• Decrease in general vision: 12, 13, 16, 17, 18, 19<br>• "I have blurriness": 1, 3, 7<br>• "I can't read anymore": 1<br>• "I realized I wasn't reading out of one eye": 5<br>• "It's a lot of eye strain": 6<br>• Affects central vision: 10, 12, 13, 14, 16<br>• Affects of light:<br>• "Bright lights bother me": 1<br>• "I need more light": 3, 16<br>• See wavy lines: 5, 7, 10, 13 (funny lines), 14 (wobbly lines),<br>• "With the amsler grid I see wavy lines": 12<br>• "By chance, I looked out of one eye and everything was wiggly": 20<br>• See dark/gray/black spots: 7, 10, 14, 19<br>• "I have a scotoma": 9<br>• Have visual distortion: 9, 12, 14<br>• Worse before an injection: 7, 14<br>• AMD found on routine eye exam: 8, 11, 16, 18, 19<br><br>o Blurry vision: 21<br>o "At night or when I'm in crowd it's blurry and not as good but it's ok, I can see ok": 22<br>o "My vision is blurred because of the fluctuation in my sugars": 25<br>o "One eye is bad, I have a blurry spot, it's missing, it's like someone took a bit out of the center of my vision": 26<br>o "After I get treated with the injections, the clarity is just great. I've had diabetes for 30 |

| | |
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| | years so I can't remember all of my symptoms. Now its just a decrease in clarity": 28<br>o "Just a few floaters, otherwise I see good": 23<br>o "One day I woke up and everything was elongated and blurry, now my vision is much better": 24<br>o "It's hard to explain. Yes the numbers are there, I can read the small numbers but my vision is not good, I see changing colors and just have problems": 27 |
| Does AMD (DR) in general **require treatment**?<br><br>Your AMD (DR)?<br><br>**What happens if you do not treat it?** | • Yes: 1, 4, 7-14, 16, 17, 18, 19, 29<br>• Shots/injections: 1, 3, 5, 7, 8, 9, 10, 11, 12, 16, 17, 20<br>• "Shots, but they do not help in my case": 13<br>• Monitor / frequent eye exams: 19<br>• "I just get monitored I think": 2<br>• "You get monitored for dry": 14<br>• I do not know: 4, 6, 15<br>• Do not think dry requires treatment: 10, 11, 16 *(Wet/Dry, Wet OU, Dry with GA OU)*<br>• Vitamins / AREDS: 12, 16, 18, 19<br>• Guess it requires treatment:<br>• "I would think that the injections are treatment": 3<br>• "I am sure it does. Well I guess I get injections": 5<br>• Do not know if it requires treatment: 6, 15 *(both were Dry AMD OU)*<br><br>• You go blind if you do not treat it: 1, 3, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 19, 20<br>• Your vision worsens: 2<br>• Do not know what happens if you do not treat it: 4<br><br>o Yes: 21-28<br>o Monitoring: 25<br>o "I go to my primary care doctor and come here ("YEC") and get seen": 21<br>o Shots: 23, 25<br>o "I got shots in both eyes": 22 |

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| | ○ "He tried giving me shots a few times but they didn't work so now we might do a laser": 26<br>○ "The shots are great, I get more clarity after them": 28<br>○ Surgery:<br>○ "I've had two vitrectomies": 23<br>○ "There's a procedure where they remove all of the blood": 27<br>○ Laser: 23, 24, 25, 27<br>○ "I got laser before in another state": 22<br>○ "I've had the laser before but I think the damage was too severe for it to do anything": 28<br>○ You go blind if you do not treat it: 21-28 |
| Do you know if there are different types of AMD (DR)?<br><br>What are they?<br><br>The differences? | • Yes: 2, 3, 5-12,14, 16, 18, 19, 20<br>• Wet and dry: 2, 3, 5, 7, 9-12, 14, 16, 18, 19, 20<br>• There are different types but do not know them: 6, 8<br>• Do not know the differences: 6, 13, 15,<br>• "I get injections but do not know the difference": 17<br>• Dry is less serious:<br>• "I take AREDS": 7<br>• "The only treatment for dry is AREDS2 to prevent progressing from dry to wet: 9<br>• "Dry has atrophy": 16<br>• "Dry is not bleeding and goes more slowly: 20<br>• Characteristics of wet:<br>• "Wet is leakage": 9, 10 (*unsure of leakage of what*)<br>• "Wet has blood leakage": 14<br>• "Wet is bleeding": 20<br>• "Wet has bleeding and inflammation": 11<br>• "Wet gets shots because of the fluid": 18<br>• "Wet not as good and you can get an operation or laser for it for it": 19<br>• No, there are not different types: 15 |

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| <u>DR only</u>: Do you know if you have PDR or NPDR? | • Do not know if there are different types: 13, 17<br>• Did not ask question to 2 people<br><br>o No, do not know if there are different types of DR or if have PDR or NPDR: 21-28<br>o "Those are new words to me": 24<br>o "I heave heard of it ("PDR and NDPR") but don't know the exact difference: 23<br>o "I assume so, there are stages, like you get floaters and then other things happen": 27 |
| What are your **concerns** regarding your AMD (DR)? What **motivates** you to come to your appointments? | • I have no concerns: 4, 15<br>• Blindness / do not want it to get worse: 2, 5, 6, 8, 9, 11, 12, 13, 14, 16, 17, 18<br>• Want it to get better: 1<br>• Treatment related:<br>• "I'm ok as long as these shots keep working": 7<br>• "My biggest concern is that the shots keep working": 20<br>• That there is no cure: 9, 13, 19<br>• Physician-related / That I have a skilled physician to control my disease: 3, 19<br>• Lose independence: 10, 17, 18,<br>• "I don't want to be helpless. I need to take care of others. Helplessness is my concern": 6<br>• "Worry that I will depend too much on my family": 11, 13<br>• Other eye turns wet: 9, 14<br><br>o No concerns: 21, 22<br>o Blindness: 23-28<br>o "I fear going blind everyday": 27<br>o Concerned about other eye conditions:<br>o "I also have glaucoma and I'm scared about that": 21<br>o Financial<br>o "I am scared that my insurance (Medicaid) is not allowing me to get the best care, it's a fear of mine. I am very concerned that there is more to get and I'm not getting it": 27<br>o Physician-related: |

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| | ○ "I know that my doctors are doing their best but concerned if not:" 22<br>○ "I have to move and am worried I won't find as good an eye specialist elsewhere": 23 |
| Do you feel as if you **understand the disease** better now than at diagnosis?<br><br>Do you need more education? | • Yes: 1, 5, 7, 9, 10, 11, 12, 13, 14, 16, 18, 20<br>• No: 2, 6, 8, 15, 17, 19<br>  • "I still just know the basics": 3<br>• "**Did not think it was a disease**, I just get injections": 4<br><br>• Yes, I would like more information: 6, 19<br>  • "I **did not know I really had macular degeneration**, I just take the Ocuvite": 15<br>• No, I have enough information: 8, 9, 10<br>  • Have learned from internet / credible sources / physicians:<br>  • "I get all kinds of info from **Bausch and Lomb** but then I read it and forget it": 3<br>  • "I bought a **book** and I trust **you people** to tell me all I need to know": 5<br>  • "I did research on my own on **internet** and the residents and **doctors** taught me a lot": 7<br>  • "Doctor gave me **pamphlet** of information and a website so I have gone to the **internet"**: 12<br>  • "I research online and my friends tell us about it": 13<br>  • "I receive **booklets** and pictures here and from the **Internet**. I don't know the terminology, but I know the things to look for and to call if I feel like there is a change": 14<br>  • "I have information **pamphlets** and look things up on **internet"**: 16<br>  • "The **doctor** tells me what I need to know": 18<br>  • "I read about it **online"**: 20<br>  • Fear knowing more:<br>  • "I believe a little knowledge is a dangerous thing": 9<br>  • "I fear knowing more": 10<br>  • "I wish people could tell me that I wont go blind, I'm afraid to research it, **depressed about it**, I guess I would like more information from the doctor |

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| | versus looking it up so that I had a physician there to ask questions to": 11<br>• "I'm ok; I don't want to know more": 17<br><br>o No, I do not understand the disease better now than at diagnosis: 21<br>o Yes, I understand the disease better now than at diagnosis: 22-28<br>o "Now that I'm more educated about my diabetes, you know before I was doing bad stuff to my body, now I want to take much better care of it": 27<br><br>o Yes, I would like more information: 21, 22, 27<br>o "More information is always good": 25<br><br>o No, I have enough information:<br>o Have learned from internet / credible sources / physicians<br>o "I have a **book** and read the **news"**: 23<br>o "I ask a lot of questions when I am here ("YEC") and **everyone** is more than helpful": 24<br>o "The **doctor** tells me what I need to know, I **leave it up to him** to tell me": 26<br>o "I'm **committed to seeing a good doctor** as often as he wants me to come, he can tell me the information then": 28<br>o Fear knowing more:<br>o "It's a bad disease. I **don't want to know** the worst of it": 28 |
| How did you come to the Retina Clinic at the Yale Eye Center?<br>By whom were you **referred?** | • Yale Health Plan: 1, 3, 9, 10, 11, 16, 17<br>• Optometrist who found AMD during annual exam: 7, 8<br>• Ophthalmologist: 6, 14, 15<br>• "Yale Eye Center physician": 4, 18<br>• "Eye doctor, yes I think it was an ophthalmologist": 2<br>• General practitioner told me to come to Yale 5, 20<br>• Friend recommended that I come to Yale: 2, 6, 13<br>• Researched on internet that Yale was the best: 12<br>• Wanted to come to Yale: 19 |

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| | • Wanted a second opinion: 7<br>• Did not like previous physician: 12<br>  • "My previous physician told me I was going blind, so I decided to come to Yale and get the best care. I got enrolled in a study and immediately I got better, it was miraculous": 20 |
| Were there any issues? | • No issues getting appointment: 1, 2, 4, 5-8, 10,11, 13-19<br>  • "The Yale Health Plan even made the appointment for me": 3, 9<br>  • "I was in a two year study here so I got good attention": 20<br>• Yes, issues getting appointment<br>  • "It took me more than 4 weeks to get my first appointment": 12 |
| What were your **fears** in coming? | • No fears in coming to the Yale Eye Center: 2, 4, 7, 10, 13, 15, 16, 17<br>  • "No fears, because I **did not know what was going on**": 8, 18<br>  • "I had more concern than fear, I know I'm old. I expect things to happen to me in the 8th decade so I wasn't too surprised. I **didn't fear that I'd go blind because the doctor reassured** me": 3<br>  • "No fears coming because I considered it a big problem and wanted the **best treatment I could find** in the area": 5<br>  • "I figured they are here to help me so I wasn't scared to come": 6<br>  • "No fears because I was happy to **hear how advanced these physicians** are": 19<br>• Yes, I had fears in coming to the Yale Eye Center: 11<br>  • "I'm scared when talk about your **vision** and I wondered if it was really a **serious** problem": 1<br>  • "Oh, I feared what I'd find out about my eyes": 12<br>  • "Very fearful because I looked up the disease on the internet": 9<br>  • "I moved and I feared changing doctors because I was doing well and I was scared with the change in provider": 14<br>  • "I was scared because did not know what was going on. But I was **glad** to be at **Yale** |

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| | **because it's the greatest"**: 20<br><br>o Family member works for the hospital: 21<br>o Primary care physician recommended I come to Yale: 23<br>o Yale Diabetes Center clinic recommendation: 27, 28<br>o Friend recommendation: 22, 25<br>o Free health clinic (Hill Health Center) referral: 24<br>o Wanted a second opinion: 25<br>o **Did not like my previous physician so I switched** to Yale: 22, 26<br>o "I had good insurance. I just don't think my doctor knew what he was doing": 26<br><br>o No issues getting appointment: 21, 22, 24, 26-28<br>o "Yes there was issues<br>o "It **took awhile to get appointment**, but I don't remember how long": 23<br>o My first appointment wasn't for months and I was nervous about that. My friend who told me to come to the eye center helped me get the appointment for sooner": 25<br>o<br><br>o No fears in coming to the Yale Eye Center: 21, 22, 23, 26<br>o Yes I had fears in coming to the Yale Center:<br>o "I feared about the diabetes and **what it would do to my vision"**: 24<br>o "I **feared the diagnosis** and basically hearing what I already thought might be true": 25<br>o "I had a lot of anxiety about my eyes": 27 |
| Were their **financial restraints that altered the care** you previously | • Previously, no financial constraints: 1, 3-8, 10-19<br>• "I was on a study and they paid for everything, including transportation": 20<br>• Previously, yes financial constraints:<br>• Insurance-related:<br>▪ "I'm on Title 9 insurance. Yale takes it but some places do not": 2 |

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| received?<br><br>Currently? | ▪ "My benefits are **linked to my job at Yale**, so I had to **wait until I got my job back** to be seen for eye care": 9<br><br>• Currently, no: 1-20<br>• *Many noted that they had "good insurance" that paid for their injections and that the Yale Health Plan was good but linked to their jobs. One respondent noted that he got supplemental insurance simply to cover his eye care and another that they would simply not be able to afford the treatments without insurance*<br><br>o Previously, no: 21, 22, 27<br>o "I had BCBS before but then I moved and its all different now": 27<br>o Previously, yes:<br>o "I was rich before but then got kidney failure and it took everything, luckily American Kidney Foundation paid for all of my care before I got Medicare": 23<br>o "I had good insurance but then my **company went bankrupt** and I lost my job so I **couldn't get care for awhile**": 24<br>o "I didn't take one of my **glaucoma drops** because it was too expensive**":** 25<br><br>o Currently, no: 21-24, 26<br>o Currently, yes:<br>o "I can't afford the glaucoma drops so I asked them to find me some less expensive ones. They were $160/month": 25<br>o "I don't like my insurance (Medicaid). I don't think it covers everything I need for my eyes and I hope that they aren't not giving my care because of it": 27<br>o "Well sometimes I put off the appointment – say the doctor tells me 6 months well I'll make it 8 because of the big copay. It's $45 each time I visit here. But if I get the pictures or the laser, it's one stop shopping. It's all included": 28 |
| Have you ever **missed or avoided** an appointment? | • Fear of pain<br>• No: 1-20 |

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| If so, why?<br>**Fear of pain**?<br><br>**Transportation** issue?<br><br>**Wait** time?<br><br>**Communication** issues?<br><br>**Illness**, etc.? | • Transportation issue<br>  • No: 1, 2, 4, 6-17, 19, 20<br>  • "Transportation issues are hard but I'd never miss an appointment, its just really expensive for me to get here (Yale Eye Center)": 5<br>  • "I have transportation issues because its hard for me to drive after dilation and the Madison town shuttle only operates on M/W/F so I have to make do, I drove myself up until recently and I probably shouldn't have, but I can't afford to pay a driver": 18<br>  • Yes:<br>  • "There was a time when I wasn't driving because of my vision and could not get a driver": 3<br><br>• Wait time<br>  • Quasi:<br>  • "I have never left but it seems like forever waiting here": 2<br>  • "I don't care about the wait but it's my driver and my husband I feel badly for": 3<br>  • "Only thing I don't like it the wait": 4<br>  • "The wait time is aggravating but I do what I have to": 6<br>  • "The wait time is a concern but I still come": 8<br>  • "Definitely, the wait time is a concern but of course I still wait": 9<br>  • No: 1, 5, 7, 11-20<br>  • "Things seem to be on time here, I understand that you have to wait especially since you dilate the eyes and do so many tests": 10<br><br>• Communication issues<br>  • No: 1-5, 7-20<br>  • Quasi:<br>  • "If I'm confused I call here ("YEC") and they explain my appointment details to me": 6 |

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| | • Illness<br>  • No: 1-6, 8, 10-13, 15-19<br>  • Yes<br>  • "I once missed because I had to have surgery": 7<br>  • "One time I had to reschedule because I was sick": 9<br>  • "I've had to postpone appointments for my own surgery and other medical reasons": 14<br>  • "My **husband died** but I **came a few days later** because I **know** how **important** these **appointments** are": 20<br><br>• Other, none: 1-20<br><br>o Fear of pain<br>  o No: 21-28<br><br>o Transportation:<br>  o No: 21, 23-28<br>  o Yes:<br>  o "Once my medical transport did not show up so I couldn't go to my appointment": 22<br><br>o Financial:<br>  o "The way I avoid an appointment is financial. Because I'm putting off seeing him for a few months longer because of the copay. Now, I put money in a savings account just for copays, and when I need to come I take money from there": 28<br><br>o Wait time<br>  o No: 21-28<br>  o "The wait time is not unduly long. They let me know if it will take awhile": 23 |

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| | o "Wait time is long but not enough to make me cancel appointment": 24<br>o "I just ask for the first appointment so the doctors are fresh and less chance I'll have to wait as long": 27<br>o "Oh the wait time, it can take hours but what I like about Yale is it's one-stop shopping. I get everything done on the same day – the tests, the pictures, the laser you know": 28<br><br>o Communication issues<br>o No: 21-28<br>o "They ("the receptionists") usually call me if there is an issue": 23<br>o "They ("the receptionists") are good about calling if there is a change in schedule": 24<br>o "The only thing I don't like is, well the ladies at the front desk, they are not warm. Sure they make the appointment and all, but they aren't welcoming and don't like to joke with me": 28<br><br>o Illness:<br>o No: 21, 22, 24, 25<br>o Yes:<br>o "One time I was hospitalized for my kidney transplant": 23<br>o "I only missed when I was in the hospital": 26<br>o "I once didn't come for a whole year, I wasn't in a good place with my health or finances and just couldn't come": 28<br><br>Other<br>o Eye reasons:<br>o "Once I just did not want to be dilated so I didn't come": 23<br>o "Actually the fear of going blind, I really don't want to go blind and it's very scary seeing blind people here ('YEC') so that motivates me to come": 27<br>o Forgot: "One time I forgot I had the appointment": 24 |

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| | o Work: "Sometimes I get last minute jobs and I have to go to them, I will call and cancel though": 24 |
| <u>AMD only:</u><br>Do you **take PreserVision?**<br><br>Any **problems buying or finding** it at the store?<br><br>Ever **not bought or taken it because** of the cost? | • Wet OU so do not take: 1, 4, 13<br>• Wet OU, took previously: 5, 8<br>• Wet OU, took previously but now smokes so stopped (despite also no longer being Dry): 3<br>• Wet OU: "I did not realize it was just for dry AMD because I still take it": 18<br>• Did not ask: 2 (Dry OU)<br><br>• No problems buying/finding it: 5, 6, 7, 8, 11, 12, 15, 17, 18, 20<br>• Yes problems buying/finding it:<br>  • "I think it's **easier** to buy it off the **internet** because it's **hard to find in stores"**: 9<br>  • **"Drugstore runs out so then I have to go back again later": 10**<br>  • "PreserVision is not always at the stores, **sometimes it says different things so I have to go to many stores": 14**<br>  • **"It's Difficult to find** in stores, so I have to **go to a few": 16**<br>  • "Sometimes stores **sold out** and they have to special order it: 19<br><br>• No problems with the cost: 12, 14, 15, 17<br>  • "It's expensive but I have to buy it, and preserVision sends me **coupons":** 6<br>  • "Buy it in **bulk** at **Walmart or Target":** 7<br>  • "I buy at **Priceclub,** because get **bigger bottle** there and it is **less expensive":** 9<br>  • "I get it in **bulk at Costco":** 11<br>  • **"Expensive but prioritize it":** 16<br>  • "It is **expensive** but I **still take it":** 18, 19<br>  • "I'd **find a way to pay** for it**, I'd give up other things** first"**:** 20<br>• Yes problems with cost: "I thought about **not taking because** of the cost especially if **not 100% effective** so sometimes I would not take it": 5 |

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| Take it **everyday?**<br><br>The **size** of the pill troublesome?<br><br>Ever not take because you take **too many pills?** | • Yes, take it twice daily: 6-12, 14-18, 20<br>• No**:**<br>  • "When I was dry, I did not take everyday **because I wasn't sure how effective it was but now I'm wet so don't have to worry about that":** 5<br>  • "Sometimes **I forget to take the second dose":** 19<br><br>• Size of pill is OK: 5**,** 6, 9, 11, 12, 15, 17, 18, 20<br>  • "It's a **capsule** so it goes down nice and easy": 10<br>  • "It's a gelcap so it's easy to take": 19<br>• Yes:<br>  • "Well, the size of the pill is big so I have to **take it alone":** 7<br>  • "Have to **crush** it and put in applesauce": 14<br><br>• No, never did not take because of too many pills: 5, 6, 7, 8, 9, 11, 12, 14-20<br>  • "It's the only vitamin I take so I take it": 6<br>  • "I take a lot of pills but of course I still take it": 10 |
| What **medication** are you on? **Before** and **now**? | • Dry AMD: participants 2, 6, 15, 16<br><u>Before</u><br>  • Avastin: 4, 7, 9 (It's off-label), 11, 12, 13<br>  • Lucentis: 14, 18, 19, 20<br>  • Eylea initially: 10<br>  • Do not know name: 17<br>  • "The old one": 1, 3<br>  • "Something that starts with an 'a'": 10<br><u>Now</u><br>  • Avastin: 12<br>  • Eylea: 4, 7, 9, 10, 13, 14, 18, 19, 20<br>  • Do not know name: 17 |

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| Do you **want a different one**?<br><br>Did you not get it because of **financial constraints?** | • "The new one": 1, 3<br>• "It's a shot": 8<br>• "Something that starts with an 'e'": 10<br><br>*(TIME SINCE DIAGNOSIS WAS NOT RECORDED BUT MANY PATIENTS WERE ON PREVIOUS ANTI-VEGF TREATMENTS INDICATING THE LONGEVITY OF THEIR CONDITION)*<br><br>• No, I do not want to change (and in general are happy with the results): 4, 9, 11, 13, 17<br>  • Related to physician's recommendation:<br>  • "They said it ("Eylea") might be more effective": 3<br>  • "I heard this medicine ("Eylea") is better so I want this one and my insurance pays for it": 8<br>  • "I have to pay more for Eylea but **I trust the doctor** that it is better so I will pay for it": 18<br>  • "I want this ("Eylea") because **doctor says that it is best"**: 19<br>  • "I **don't see any difference, so whatever the doctor thinks is best"**: 20<br>  • Related to experience with Eylea:<br>  • "This is the new one and my insurance will cover it": 1<br>  • "They said this one might be more effective": 3<br>  • "I have less blurriness and pain after my injection now": 7<br>  • "I like Eylea better because **come can less frequently"**: 14<br>  • "I believe I've only had one kind I think": 10<br>  • **"I heard there is a more expensive one ("Eylea") and my insurance will pay for it, but this one ("Avastin") works so I have no reason to switch": 12**<br><br>o Avastin: 24, 27<br>o Do not know name:<br>  o "I get the shot": 22 |

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| | ○ "Yes, I get an injection. Not sure what it's called though": 26<br>○ "It starts with an 'a-v'": 28<br>○ Do not / have never received intravitreal injections for their DR: 21, 23<br>○ "I have never had the Avastin, the doctor offered it to me but I refused": 25<br><br>○ No do not want another, this works: 22, 24, 27, 28<br>○ "The injection worked at first but then did not help so we might do laser now. No, I do not want another": 26 |
| What was your **fear before you had your first** injection?<br><br>What about **now?** | • Dry AMD: participants 2, 6, 15, 16<br>• Did not ask: participants 1-6<br><u>Before</u><br>• Fearful:<br>• "The whole **idea of a needle in the eye** is frightening, told that it don't feel it but you don't believe it, you cant blink but you see it coming, it's just awful": 7<br>• Very fearful and nervous something would happen to my eye: 9, 11, 12, 13, 14, 17<br>• Pain<br>• "I was very **scared** for the **pain"**: 8<br>• "I knew other people who had it, but I still had fear and apprehension for the **pain"**: 10<br>• No fear:<br>• "It was **so fast, I had no time to think** so I wasn't scared": 18<br>• "I'm afraid of doing anything to the eye, but **realized I would go blind if did not do it": 19**<br>• "I had **read about it**. I wasn't excited but you do what you have to do": 20<br><u>Now</u><br>• Still fearful:<br>• "I'm still anxious but **less than before**, I take an **antianxiety pill** before I come": 11<br>• "I'm not excited about it, I'd say its more that I'm **uncomfortable**. I do **not want a** |

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| | **fellow or resident** doing the injection; I **do not want someone practicing on my eye**. I know it's selfish. I **fear they will make my condition worse"**: 13<br>• Oh yes, I still have fears about my eye getting injured before the injection": 17<br>• Not fearful: 8, 18<br>• "Now the **choice is going blind** versus getting the shot, it's still **uncomfortable**: 7<br>• "Scared when waiting to hear results of tests but **not of injection itself, I take a pain pill before I come": 9**<br>• "Not fearful because it does **not hurt at all"**: 10<br>• "I come **mentally prepared and expect** that I will get injection and that helps": 12<br>• "My fears **do not outweigh losing my vision so no fears now"**: 14<br>• "I'm better about it now, **but worry that he (the physician) is doing it correctly**, and I do not like the **pressure"**: 19<br>• "It **still hurts** so I sleep for a few hours after the injection and keep my eyes closed but then it's better by the next day": 20<br><br><u>Before</u><br>o Do not receive: 21, 23<br>o "The **doctor offered** it to me, but I **refused**. The **thought of it just made me sick**. No thank you. I'd take the laser over that": 25<br>o Not fearful: 26, 27<br>o Fearful<br>o "It was a temporary pain and fearful feeling": 22<br>o "I felt apprehensive about it all": 24<br>o "The numbing drops help a good deal, its more pressure and the **idea of it**, a needle in the eye is still scary": 28<br><br><u>Now</u><br>o Not fearful: 26, 27 |

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| | ○ "The ends justify the means": 22<br>○ "It is much more tolerable now and I do what I have to for my eyes": 24<br>○ "I've come to accept it. But I'm still glad that I didn't get it when I didn't need it": 28 |
| DR only:<br>What is your experience/stress with the laser? | ○ No stress: 21<br>○ "It's a temporary pain": 22<br>○ "I'm emotional. It is unnerving having no control of your eyelid and getting the pulses: 23<br>○ "It is better than the injection and is not painful, only a very bright light": 24<br>○ "The laser is kind of scary. I counted 89 zaps one time. It felt like it was making a hole in my head. I'm not scared though; I am tough. I felt more apprehension at first but Im fine now": 25<br>○ "It's painful, but not the most pain I've ever had": 27<br>○ "Injection is more uncomfortable but its quick with the laser you have to keep your eye still and I get nervous that they will burn something off because I have a lazy eye and it moves. I'm less nervous now": 28<br>○ Have not had: 26 |
| DR only:<br>What does the laser do?<br><br>What does the injection do? | Laser<br>○ "Docs give you laser when your sugars are bad. I don't think the laser does anything but the doctor says I have to have it": 21<br>○ Bleeding:<br>○ "It helps with the bleeding": 23<br>○ "It cauterizes the vessels so they don't bleed": 24<br>○ "Plugs up the leakage of new blood": 25<br>○ "Severs the vessels so they stop leaking blood": 27<br>○ "Seals the blood vessels. It burns them I guess": 28<br>○ Do not know: 22, 26<br><br>Injection<br>○ Swelling: 27<br>○ "It helps with the swelling: 24 |

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| | ○ "It is supposed to help with the swelling": 26<br>○ "The injection stops the blood flow": 25<br>○ Do not know: 22, 28<br>○ Have not had: 21, 23, 25 (*but still answered what it does*) |
| Do you feel as if coming to your appointments at the Yale Eye Center **is important for your health?** | • Yes: 1-20<br><br>○ Yes: 21-28 |
| Who brings you to your eye appointments? | • Drive self: 2, 4, 7, 8, 10, 12, 16, 17, 18<br>• Spouse drives: 1, 3, 6, 7, 11,12,13<br>• Children drive: 20<br>• Walk: 9<br>• Paid Driver: 5, 14, 15, 19<br>• Free rides (Myride/Town Jitney): 8, 18<br><br>○ Drive self: 25, 27<br>○ Spouse drives: 26<br>○ Children drive: 21, 25<br>○ Walk: 24<br>○ Bus: 24, 28<br>○ Free ride / Medical taxi: 22, 23 |
| What is **your expectation of the medical treatment** you receive at the Yale Eye Center? | • No expectations: 4, 11, 16 (Because my condition does not have any treatment)<br>• Related to vision:<br>  • "Hope that my vision will get better and I can read newspaper": 1<br>  • "That I won't go blind": 3<br>  • "Possibly improve or stabilize my eyes": 5<br>  • "Stay the same or not get worse": 7<br>  • "At least keep me stable and able to see": 8 |

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| Are you satisfied? | • "My hope and expectation is to control my eyes": 9<br>• "At least level off, will not get any worse": 10<br>• "That my vision gets better": 13<br>• Related to physician:<br>• "They always tell me everything is fine, so I think its fine": 2<br>• "That you do everything to help my eyes": 6<br>• "That he tells me the truth and is honest and provides the best care": 12<br>• "That you give me the best care": 14<br>• "That you guys keep my eyes working": 17<br>• "That I will get the best treatment at Yale": 20<br>• Related to finding a cure / medical research:<br>• "I expect that if there is a cure or experimental treatment that I can be a part of that treatment": 9<br>• "I'm hoping that research will be discovered and make my eyes better": 13<br>• Did not ask to 1 participant<br><br>• Yes, I'm satisfied: 3, 4, 6, 12, 13, 18, 20<br>• "I'm satisfied or I wouldn't be here": 2<br>• "It's good that you use the **new medicine** for the eye because I don't mind the injection": 3<br>• "They are very thorough; they do so **many tests** and before I came here I **used to get conflicting answers** with what should be done with my eye care but here there is no questioning": 5<br>• "I'm very satisfied because vision has stayed the same": 8<br>• "Yes, I get excellent care and I **feel fortunate that insurance covers it":** 11<br>• "The hardest part is the delays in between, my visit takes at least 3 hours and because I need a driver to bring me it's hard but I'm satisfied with my eye care and my eyes": 14<br>• "Sure, it ("care at the YEC") is the best the can be rendered despite my condition not having any treatment": 16 |

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| | • "Yes, I like my doctor": 17<br><br>• No, I'm not:<br>• "I will only be satisfied if my vision improves": 19<br><br><u>DR expectations</u><br>o Related to physician:<br>o "I'm 82 years old and doctors are trying to the best of their ability to save my vision": 22<br>o "To tell me what's wrong and if they can fix it. If I'm doing ok, please tell me and I want to know that they know the newest technology": 23<br>o "Well I expect the best treatment otherwise I'd stay local. You hear the word Yale and you want to go there. You expect the physicians to be the best. I just want my doctor to treat me properly": 25<br>o "For him to to take care of me properly and get me the best treatment available if needed. I understand the Eye Center can't solve my problems or control my blood sugar but I expect you guys will treat effectively whatever I do to myself, which sounds stupid, but if I wasn't doing A, B, and C to myself then I wouldn't need to come": 28<br>o Related to vision:<br>o "Even if it doesn't get better, not to get worse": 24<br>o "Just stabilize my vision and keep me seeing": 27<br>o Related to technology:<br>o "I want to know that they know the newest technology": 22<br>o "I want them to use the new technology on me": 24<br>o That it's good: 21<br>o The best possible: 26<br><br>o Yes, I'm satisfied: 21-28<br>o "They are very thorough and do a full eye exam each visit": 24<br>o "100% satisfied": 27 |
| What is **your** | • Honesty: |

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| **expectation of your communication** with your Yale Eye Center physician? | • "I like the doctor to be honest with me and to know if my condition is serious": 1<br>• "Just want them to be honest": 2<br>• "I just hope they tell me how my eyes are doing": 4<br>• "I believe that they will tell me the truth with the status of my eyes": 16<br>• Stay the same: 5<br>• "While I'm here I think it's good": 3<br>• "He is very thorough": 6<br>• "We get along quite well": 7<br>• "I think it's good": 8<br>• "I want it to continue the same, I think we have good communication": 9<br>• "I switched from a community physician and this is better than previous doctor": 19<br>• "I get all my questions answered so that's good": 20<br>• Related to understanding:<br>• **"The doctor knows what I understand and what I can not": 9**<br>• "Sometimes the **doc tells me more than I want to know or understand": 10**<br>• "My expectations are that I will understand what he tells me and that I can ask questions when I have them": 16<br>• "It's difficult for me to understand his accent": 19<br>• Desire more time for questions:<br>• "I expect doctor **to spend more time explaining** and talking about prognosis, its important to have that **face time"**: 11<br>• "I **feel guilty to voice my opinion** or ask too many questions of the doctor": 13<br>• "I do not have my questions answered. I'm **scared to ask the doctor** but I tell and ask the technicians and have them write down all the information in my chart and I think it gets passed on": 14<br>• "I **wish he could chat more, but he is too busy"**: 17<br>• "With the **new computer** system I feel like there is **not as much time to talk to doctor** and get to see the photos of my eyes": 18<br>• "Sometimes the doctors **move very quickly** and I feel as if they are rushed": 19 |

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| Are you satisfied? | • Did not ask to one participant<br><br>• Yes: 1-10, 12, 15, 16, 18, 19, 20<br>  • "While I **wish he could chat more**, I know he is too busy. **So I am still satisfied**": 17<br>• No:<br>  • "Wish I had more time to talk with physician": 11, 13, 14<br><br><u>DR expectations</u><br>o Related to understanding<br>  o "It's good because my son or daughter translate for me": 21<br>o Related to honesty:<br>  o "Just to tell me where I am at because I ask a lot of questions": 24<br>  o "To tell me like it is": 26<br>  o "To be honest with me and give me all the available options regardless of if it's covered by my insurance or not. That's what I fear is that I won't get something because of my insurance ("Medicaid") but it there's a better option I'll find a way to pay for it because these are my eyes": 27<br>o "Very nice": 22<br>o "We do ok. I sometimes ask the docs to wash their hands. I **never feel scared to questions**": 23<br>o "Everyone is very nice. They ("the receptionists") call to remind me and to remind me to bring paperwork and stuff": 25<br><br>o Yes, I'm satisfied: 21-28<br>  o "I'm satisfied, but he's quick sometimes. I **would like more time** with him and **not with the students, research associates, interns, whoever you all are.** Sometimes there are apologies because it takes so long and there are difficult patients, I understand that. And he told me that whenever he is looking at the computer in the hallway he is looking at my case and my photos, so that makes me feel better. Another thing is I swear when the ("technician") takes me back and asks me all those questions and writes down my complaints, I feel like the doctor never responds to those. I'll have |

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| | to bring them up again and make sure I ask my questions but I guess they weren't that important": 28 |
| Do you have a **primary care doctor (PCP)?**<br><br>Do you see him/her regularly? | • Yes have PCP: 1-18, 20<br>• No have PCP: 19<br><br>• Yes, see regularly: 1, 3-18<br>• No, do not see regularly:<br>  • "My insurance does not let me see him enough": 2<br>  • "I **consider myself healthy for mid-80s**. I only see a doctor if I need surgery or the eye doctor **so I don't go to a primary**": 19<br>  • "I don't always go to doctor": 20<br><br>o Yes have PCP: 21-23, 25-28<br>o No do not have PCP: 24<br><br>o Yes, see regularly: 21-23, 25<br>o No, do not see regularly:<br>  o "No, I do not see him regularly. I can't afford it and I don't have the time": 24<br>  o "No, I see my endocrinologist more. I don't get annuals": 25<br>  o "I have issues with her. I like my diabetes docs": 27<br>  o "I can't afford the copay if I don't need to see them": 28 |
| Do you feel as if there are any barriers to you receiving eye care?<br><br>What can the medical profession and health care system do to reduce barriers to receiving | • There are no real barriers: 1 - 20<br>  • "I feel good with the care I am receiving": 2<br>  • "I do not feel as if there are any barriers": 3<br>  • "I have a supportive, helping family so that makes a huge difference": 11<br>  • "We are happy with the care we get": 12<br>  • "They ("Yale Eye Center team") have become part of my family": 17<br>• To help with AMD |

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| proper AMD care?<br><br>Anything to make your experience better?<br><br>Anything to help with your AMD (DR)? | • More information: "I'd like information pamphlets": 1<br>• Honesty: "I just like the doctor to be honest with me and to let me know if my condition is serious": 5<br>• Eye care:<br>• "Do not give me dilating drops if I do not need them": 2<br>• Financial:<br>• "Before I had the good insurance I had problems with paying for the medicines but I'm OK now": 5<br>• "If I lose my insurance or lose my job than I lose my insurance so for me it's **not about getting healthcare but losing healthcare"**: 9<br>• Wait time:<br>• "You can just keep the patients moving and not wait for too long": 4<br>• "Nothing to make it easier, only thing I don't like is waiting": 6<br>• "The appointment can take at least 3 hours, it's lengthy but it works and we plan for it: 7<br>• "You can reduce the wait time": 16<br>• "The appointment kills an entire afternoon": 19<br>• "Just work on the waiting, it kills me": 20<br>• Scheduling<br>• "The only trouble is getting an appointment sometimes but I can always get one just not for when I want it": 7<br>• Parking:<br>• "Parking is difficult and costs a lot": 10<br><br>o No real barriers:<br>o "Nothing, it's good": 21<br>o "They are doing their best": 22<br>o "There are no real barriers": 23<br>o "They are doing everything that they can": 24<br>o Financial: |

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| | ○ "It's just that cost of most prescriptions. They are overwhelming for me": 25<br>○ "Just give me all the available options regardless of if it's covered by my insurance or not. That's what I fear is that I won't get something because of my insurance ("Medicaid") but it there's a better option I'll find a way to pay for it because these are my eyes": 27<br>○ "It's hard that every time I come back to see another specialist its another $45 copay. I wish they could unite the care a little better and make teams": 28<br>o Clinic experience:<br>○ "Sometimes it is so busy in the clinic that I feel as if I am in a train station moving from room to room, bouncing around": 23<br>○ "It does take quite awhile; I'm there for 2-3 hours but I guess that can't be helped": 26<br>○ "I wish the doctor had his own office, you know a private building. I don't like the idea of coming into a big hospital every time I need to see him": 27<br>○ "What concerns me about the eye center is the amount of time the people spend looking at the computer screen. But I've talked to the doctor about it and he explained it to me": 28<br>○ "I'd love to see a summary of what the doctor thinks is going on with me. I know he sends a copy to my diabetes doctor but it would be good to have. Not just general information about my disease but what's actually going on with me": 28<br>o Related to disease:<br>○ "You can find a cure for diabetes": 4 |

*Considerations that may prevent AMD patients from seeking eye care*

Throughout all of the semi-structured interviews the participants did not remark on any clear, explicit barriers that they felt prevented them from receiving adequate, if not, exceptional care. However, when further, deeper analysis of the interviews is conducted many key issues arise that may deter as well as enable patients to continue seeking eye care once it has been obtained. Despite the differences in patient population characteristics (specifically age, gender, ethnicity, insurance coverage type and educational level) the identified barriers for age-related macular degeneration and diabetic retinopathy participants are remarkably similar with some unique aspects owing to the nature AMD.

- **Confusion and limited knowledge of AMD**

When asked directly, all of the patients interviewed were aware that age-related macular degeneration could cause blindness if left untreated. Yet when asked to elaborate on their basic knowledge of AMD 30% of patients noted that they either "do not know anything about it" or "do not know much about it" and only half specifically said that it affects or causes loss of vision. Of those who had limited knowledge of AMD the vast majority had a high school education or less. Others were confident that their other eye conditions such as glaucoma or other external factors such as sunlight exposure affected their AMD. Another 25% of participants noted that a family member went blind and therefore by default had AMD. More than a quarter of those interviewed had their diagnosis picked up on annual exam and were asymptomatic at diagnosis and some remained so currently. Interestingly, a fifth of those interviewed also feared learning

more about the disease. This acted to reconfirm their limited knowledge. One respondent noted being depressed about the diagnosis and another patient even remarked that he did not know that AMD was a “disease”. Two-thirds of the patients knew the name of the injection they received previously and currently and the remaining third were unsure.

- **Access to specialist care**

While a recurrent barrier in the medical literature is lack of access to primary care as well as to specialist physicians, as evidenced through the interviews in this patient population, all of our participants were able to reach care at the Yale Eye Center. A few noted that it took a long time to get the initial appointment and many were diagnosed by “other physicians” or referred by general ophthalmologists within the Yale Health Plan network. Except for 15% of those interviewed, the remaining AMD patients had a primary care physician and saw him/her regularly. Along with adequate access to specialists comes a transportation issue. While only one AMD patient missed an appointment because he/she could not afford a driver, another 10% noted that it was incredibly expensive and difficult for them to coordinate drivers on a monthly basis to attend clinic. Twenty percent of patients required a paid driver to attend clinic while 10% used free community-provided or medically-reimbursed transportation.

- **Financial constraints**

Beyond the cost of transportation listed above, the cost of insurance and copays are major considerations for many patients. None of the AMD participants noted direct financial constraints that altered the care they currently receive. All patients had

insurance at the time of this investigation. However, 10% noted that previously insurance issues altered their care. Further, the vast majority of patients with wet AMD who receive the newest and quite expensive anti-VEGF agent noted that without their current insurance plan (specifically, Medicare plus a secondary) they would not be able to afford the treatment. One patient even noted that he purchased the secondary policy just so that he could come to the ophthalmologist and receive this medication.

- **Difficulty buying and locating, and unsure of indications for taking, AREDS2**

Along the same lines as financial constraints comes this issue. It is recommended for patients with the less advanced forms (certain dry variants of age-related macular degeneration) to take AREDS2 (PreserVision), an FDA-approved eye vitamin and mineral supplement. (10) Nearly forty percent of those who take it noted difficulty buying or finding it in the stores. Many had to go to multiple stores to find it and mentioned that they would only buy it from bulk distributors. Further, more than sixty percent remarked on its high cost, but they all said something similar to “I would do anything to find the money to purchase it”. A few respondents with the wet variant in both eyes still took the medication, but it was not investigated further if they knew if it was only for dry AMD and/or if they had recently been diagnosed with wet and were continuing with it until they finished their current supply. There was one participant who commented that he did not always take the pill because he was not sure of its effectiveness and another who often forgot to take the second dose.

- **Frequency and length of clinic visits**

Again while no patient noted that they would not attend an appointment, the frequency at which patients with AMD, especially the wet variant, must visit the retina clinic and the length of their clinic visits serve as major deterrents. These are two key reasons why patients prefer the newer anti-VEGF treatment. Half of the patients remarked on the wait time with many reporting that a visit takes up their entire afternoon. However, once again, none of them remarked that it prevents them from coming or that it made them consider switching providers. Instead some remarked that they knew the doctors were doing the best they could and that they were grateful that all of the testing and procedures could be done on the same premises and at the same visit. There was a subset of interviewees though that responded that despite the length of the appointment that they wished they had more time to communicate with and ask questions of their primary physician.

- **Fear of requiring an intravitreal injection**

While none of the patients directly avoided an appointment due to the fear of pain, many feared receiving an injection, the idea of the needle in the eye and even the possibility of needing an injection. Most importantly, they feared that something might happen to their eye during the injection. More than half of those who were fearful before their first injection no longer felt that way. Many remarked that despite it being uncomfortable it was a necessity to preserve their sight.

- **Others barriers**

Additional recurring comments included the participants fear that there is no cure for AMD or that their other eye progresses to the wet variant of AMD, and that they hoped that the injections keep working. Many had the expectation that the physician and the care they receive should be able to maintain or perhaps improve their vision, and only one respondent was dissatisfied because her vision had not improved.

*Enabling factors that motivate patients to seek care:*

- **Positive attitudes about vision and eye care**

All patients agreed that coming to the Yale Eye Center and having ophthalmic examinations was of utmost importance to their health. Thirty percent also noted that a major concern for them was the potential loss of independence and reliance on others that would could from blindness. These concepts directly motivated patients to seek care.

- **Confidence in their providers**

Many respondents stated that they had complete trust in the physician and their physician's medical decisions. Some commented that they were grateful that they were receiving the newest and most effective medication for their condition. The vast majority was very satisfied with the overall medical treatment and with the communication with the providers. They also predominately trusted the physician's judgment on information sharing and to tell them what knowledge they needed to know about their condition.

## V. DISCUSSION:

As presented in the Introduction there were six overarching barriers that are common among diabetic retinopathy patients. After conducting twenty in-depth semi-structured interviews with age-related macular degeneration patients at the Yale Eye Center we conclude that despite the differences in the patient populations and the disease entity, we find the overall barriers markedly similar with notable unique elements particular to age-related macular degeneration. These distinct aspects most likely owe to the nature of the disease and the patient population it affects. Here we will attempt to understand each barrier category and why it affects our patient population, and make recommendations for how they can possibly be addressed.

The first issue for our participants was limited knowledge of AMD. The majority of those who lacked knowledge on basic AMD reconfirmed this barrier by also not knowing the name of the medication they receive or by making other improper conclusions such as stating “glaucoma affects AMD”. As mentioned, this group predominately had a high school education or less. This points to something much deeper than simply limited AMD knowledge. It indicates a likely limited overall knowledge foundation, which is an even larger, greater barrier. Klein et al, in a 2013 study on the prevalence of visual impairments in aging, found that patients with age-related macular degeneration are more likely to have a bachelors degree than those with diabetic retinopathy. (5) And, interestingly, in a 2010 report on diabetic patients in the New Haven area it was determined that regardless of education level, patients had little knowledge of diabetic eye disease. (25) This is so important because many studies show that a lack of awareness and/or knowledge of a disease (diabetic retinopathy in this case) may reduce the

attendance to eye clinics. (24) This could prove detrimental for AMD patients. Along those lines, thirty five percent of the patients interviewed reported that they felt as if they did not understand their condition better now than at diagnosis but yet only 15% reported that wanted more information. Does this decreased desire to learn more indicate something more significant? In order to at least address this issue in the Yale Eye Center, when patients with AMD check-out from the clinic they are given a print-out with detailed patient-directed AMD information.

Access to specialist care is the second theme that emerged from the data. While access to care is a broad, vast issue, gaining access to specialist care is even more complex. Seeing a specialist oftentimes involving obtaining a referral and a long wait period. The majority of recent studies on wait time have been conducted in the Canadian health care model, which is infamous for its lengthy waits. (32-34) A 2014 article by Jaakkimainen et al looked at wait times in Canada and found that the median wait for seeing medical specialists ranged from 39-76 days and for surgical specialists from 33-66 days. (34) While this is not currently directly generalizable to the United States population, it could be the future with our new proposed health care model. A wait time of that long for AMD patients could mean serious and perhaps permanent vision loss. A handful of our patients had their condition found on routine exam because they were initially (and a few still remain) asymptomatic. Had it not been for that visit to a general “eye doctor”, their diagnosis, and treatment initiation, would have been delayed. As previously mentioned early detection and treatment has proven helpful in slowing or averting AMD progression to more advanced, deleterious forms of disease. (6, 7) Kankanahalli et al published a fascinating new tool in 2013. They developed a quite accurate automated analysis for

classification of AMD from digitized fundus photographs and it may have a role in initial AMD screening. (35) This could be a game-changer for access issues. Another study worth mentioning was recently done in Southern Poland by Latalska et al and looked at patients from both urban and rural settings. They interestingly found that patients' place of residence had no impact on obtaining proper AMD care and that they both had adequate access owing to perhaps a sufficient level of ophthalmological care in that area. (36) If this is the case, further analysis into their health care delivery model is warranted. Our patients surveyed were mostly satisfied with their ability to easily get an appointment with a retina specialist. However, what this study, and others like it, failed to capture is the potential pool of patients who could not get an appointment (or were not satisfied with the wait time) at the Yale Eye Center and were possibly forced to seek care elsewhere or not at all. This could be due to real, pressing issues with access and specialist shortages needed to care for the aging population prone to AMD.

Third, major breakthroughs have been made in the last decade in treating AMD. The change in near-term prognosis with a 90% chance of stabilizing or increasing vision is no doubt a significant achievement owing to new treatment modalities and diagnostic tools. However, this improvement comes with the significant price tag of frequent (if not monthly) intravitreal injections and the uncertainty of how long the treatment lasts.(6) With this comes the topic of financial constraints. Many of our respondents asserted that without their secondary insurance they would not receive the newest, more expensive medication (aflibercept). There have been many studies and opinion pieces on the cost effectiveness of aflibercept and a recent cost-effective analysis by Thomas et al found that it is comparable to the other leading therapies. (37) All of our participants who

receive this medication are satisfied with it and do not want to switch to any of the other available alternatives. When probed, this is mainly because they are following and trust their physician's recommendation. The use of off-label bevacizumab, a much less expensive alternative, is beyond the scope of this study, but experts in the field favor the use of aflibercept for its potential extended treatment interval beyond monthly injections and subtle visual outcomes advantage. (38, 39) However, it is reassuring to know that for the overall elderly population, many of whom cannot afford secondary insurance, AMD treatment is covered through Medicare.

The next topic involves the indications for and the purchasing of oral supplements (AREDS initially and now AREDS2) for non-advanced forms of AMD. More than sixty percent of our participants have variants of AMD for which AREDS2 would be of benefit. While they all take it, many thought-provoking concepts arose when discussing its use. Some did not connect taking the supplement to their non-advanced form of AMD or to its power to reduce its progression (perhaps this is a difficult concept to grasp).Others who had already progressed to the wet variant continued to take it "just because" and they could not truly explain why. While this topic was not further explored during the semi-structured interviews, it will be in a formal questionnaire and allows for another point of patient education. What Burton et al found in a qualitative study of 13 AMD patients conducted in 2011 in the United Kingdom was similar: "Despite the value of taking vitamins and the recommendations for making patients aware of these, only four participants discussed the use of vitamins, and all were unsure of their purpose or which were the most beneficial to take." (21) Their expensive pricetag (about $20-$30 per month) was already discussed but none saw it as a complete barrier to purchasing.

What many interestingly remarked on was the difficulty they encountered when trying to find  2 in stores. Across the realm, many patients noted frustrations. They ranged from pharmacies needing to special order it, to needing to go to multiple stores, to relying on online buying. If this is truly an issue, perhaps the major retailers could be contacted and these impediments remedied.

Another key deterrent that patients noted was the frequency of the clinic visits and accordingly then how long they take. As mentioned, the power of aflibercept (the newer treatment for wet AMD) lays in its ability to extend time between treatments. Not needing to make monthly visits to the ophthalmologist is favorable for all parties involved. While the majority commented on the length of the appointment, not one respondent said it deterred them from coming. There is an opportunity cost to this time spent in the physician's office. This might significantly impact participants who work more so than the elderly, mostly retired AMD population. More than a third of our study population still work. We may not have captured these patients because they could not sacrifice time away from a strict job. (If this is the case, it is then hard to place a price on maintaining one's eyesight, and it is sometimes hard to remind patients about preventative medicine.) However, to better address this barrier, perhaps we could try to contact former patients to assess their reasoning for no longer attending clinic appointments. Again, many noted that they appreciated the thorough exam they received at each visit, knew that the physician was doing the best that he could, and understood that at one appointment they were not only examined but had diagnostic tests and received treatment.

The last theme that emerged was the fear of intravitreal injections. Participants seemed more fearful of the idea of the needle in the eye than the actual pain from the procedure. Many mentioned that they were more apprehensive than fearful; they noted being nervous not knowing whether or not they would require an injection. A recurring notion was the fear that something might happen to the eye, as in permanent damage from the injection. Again, no patient avoided an appointment due to this fear. They dutifully noted that it was uncomfortable but its results made it justifiable. Interestingly, Lucena et al looked at patients with high-risk PDR who needed retreatment. In a head-to-head analysis they found that patients experience significantly more pain with pan-retinal photocoagulation than with intravitreal injections using 30-gauge needles. (28) Laser photocoagulation used to be a mainstay of wet AMD treatment, but now luckily we rely more on injections. Excitedly, investigations into further reducing the pain of these injections by using 33-gauge (smaller) devices are underway. (27)

Worth mentioning are two other concepts relating to care delivery, which are especially illuminating in today's health care scene. They both deal with communication. A new study out of Northwestern University found that EHRs (electronic health records) affect doctor-patient gaze differently than paper and this most likely negatively impacts the mutual doctor-patient relationship. (40) They found the physicians spent about one-third of a visit gazing at the EHR versus about 11% with paper. Our study reconfirmed this ever-growing claim: patients desire more time, and more face-to-face time, with their physicians. As EHRs are here to stay, perhaps even something simple could be done. If the set-up of the clinical exam room puts the EHR between the physician and the patient, instead of against a wall, this could make this barrier less evident. The second concept

stems from many interview participants mentioning their desire for their physician to be honest with them about their prognosis. This was a recurring theme amongst AMD and DR patients and in the greater medical arena. The integrity of the doctor-patient relationship relies on physicians being honest with their patients and the respondents repeatedly said that; this is the Honesty Effect. (41, 42) A common response during the interviews was comparable to: "I just want him to tell me like it is".Regardless of current BCVA, interviewees were satisfied when the truth was told.

It is essential now, with this gained knowledge to prioritize and determine which barriers if eliminated or reduced would have the greatest impact on the desired future state of care delivery.

*Limitations of the Study:*

This study may have several limitations. The first is that a single interviewer conducted all interviews. This may have introduced bias into the responses. We attempted to abate this issue by using a semi-structured interview style. Further, the interviewer was familiar with all of the interviewees. Despite reassuring participants that all of the responses were confidential they may have withheld some of their opinions and reflections in fear that it would directly affect their care. To minimize this issue, if the interviewer (LBH) noted any hesitation, LBH reassured the participants to the confidentiality of the interview.

Second, this study was based in a single geographical area using patients from a single retina clinic. While the clinic attracts patients from a diverse geographical area (rural, suburban and urban) they all receive care from a single provider at a single institution.

This could negatively impact the generalizability of our findings. However, many barriers such as limited knowledge and financial constraints are unfortunately considered universal. We attempted to conduct the semi-structured interviews at the Cornell Scott Hill-Health Center, a federally qualified community health center, but could not recruit enough AMD patients, likely owing to the epidemiology of the disease. Specifically, the overwhelming majority of patients with AMD qualify for and have Medicare insurance, which is thankfully still accepted by most providers.

Third, because we were concerned with understanding the social, psychological and economical phenomena from the perspective of the study participants, and we wanted to investigate root causes and explore unexpected factors influencing these Yale Eye Center patients, a qualitative approach was taken. While we did also obtain some of the common barriers affecting diabetic retinopathy patients at the Yale Eye Center we could not do a quantitative analysis between the two. We were able to quantitatively determine which issues were more common and grouped responses accordingly to form our conclusions. All of the frequent topics that were discussed were included in the formal *Retina Clinic Questionnaire* and that data will be used for a strict quantitative analysis. Qualitative studies are not meant to produce generalizations across populations, they instead generate analytical theories and categories, which this study aimed to do.

Finally, and most importantly, is what this study failed to capture. While barriers to care are often accessed in a qualitative method as was done, the method of interviewing patients who have already reached care is inherently flawed. We need to find the patients who have not yet reached care for their AMD. Ideally, we would interview generic

elderly participants in the community outside of the medical realm, or even better patients reporting seeing “wavy lines” or a decrease in central vision to their primary doctors, and question their barriers. However, this method is likely impractical and infeasible. This is why barriers to care for less prevalent diseases (such as AMD compared to more prevalent already studied conditions such as hypertension and diabetes) are less likely studied in the literature; it is simply harder to obtain a target study population. This study sheds light on the specific deterrents that face AMD patients despite have access to care.

*Questionnaire*

Using data gathered from the semi-structured interviews we created a formal, uniform questionnaire. This assessment tool can be distributed to all return age-related macular degeneration or diabetic retinopathy patients who carry no other retinal diagnoses and who present to the Yale Eye Center’s Retina Clinic. It is self-explanatory and can be self-administered. It will be presented to the patient with a self-sealed envelope in which they can place the questionnaire upon completion. The data gathered from this questionnaire, along with the data presented here within, will be used in manuscript development.

# RETINA CLINIC QUESTIONNAIRE

**What:**

- We are asking you to participate in this questionnaire because you have **either age-related macular degeneration (AMD) OR Diabetes Mellitus** that affects your eye.
- All questions are related to the eye condition for which you see Dr. Adelman.

**Why:**

- We are interested in **learning about what you know and what you want to know** about your eye condition in an effort to **provide you and others with the best care possible!**

**More info:**

- All answers are **ANONYMOUS**.
- Your participation is **VOLUNTARY!**
- You may **skip a question** if you do not know the answer or do not want to answer.
- Please contact Laura Hall (203-868-0648) or laura.hall@yale.edu with questions.

**THANK YOU!**

1. How did you learn about the **Retina Clinic** at the **Yale Eye Center**?
   *Circle ALL that apply*
   a. Referred from Yale Health Plan
   b. Referred by my ophthalmologist
   c. Referred by my optometrist
   d. Wanted a second opinion
   e. Wanted to change doctors
   f. I was not satisfied with my previous care for my eye condition
   g. My friend recommended Yale
   h. I did research and chose Yale
   i. Do not remember
   j. Other: _____

2. Did you have any **issues** getting your **FIRST** appointment? *Circle one*
   a. Yes
   b. No
   c. If yes, explain: _____

d. Did you have to **wait a long time to get your first** appointment?
    i. Yes
    ii. No
    iii. Do not remember
    iv. If yes, explain:

---

e. Did you have any **fears** first coming to the Yale Eye Center?
    i. Yes
    ii. No
    iii. Do not remember
    iv. If yes, explain:

---

3. Have you had **any issues** getting your **appointments recently**?
    a. Yes
    b. No
    c. Do not remember
    d. If yes, explain:

    _____

4. What are your **eye symptoms**? *Circle ALL the apply*
    a. No symptoms
    b. Decrease in vision
    c. Blurry vision
    d. Problems with central vision
    e. Dark spots in vision
    f. See wavy lines
    g. Floaters and/or flashes
    h. Do not know
    i. Other: _____

5. Was your condition was found during an annual, routine exam?
    a. Yes, explain: _____
    b. No

6. Does the **eye condition** that you come to the Retina clinic for **require treatment**?
    a. Yes
    b. No
    c. Do not know
    d. If yes, what is it?

    _____

7. Do you **get injections (shots)** in your eye?
    a. Yes, what is its name? _____
    b. No (*If no, proceed to question 9*)
    c. Do not know
    d. If yes, did you **ever get a different medication before**?
        i. Yes, what was its name? _____

8. Do you or did you **want a different medication** (injection / shot)?
    a. Yes
    b. No
    c. Do not know
    d. If yes, did you have any **financial constraints or issues with getting this different medication?**
        i. **Yes, what were there? _____**
        _____
        ii. No

9. Tell us about your **experience** with the **injection (shot)**?

    _____

    a. Is the injection **painful**?
        i. Very painful
        ii. Somewhat painful
        iii. Neutral
        iv. Not very painful
        v. Not painful at all
        vi. Other: _____

    b. Is the injection **fearful**?
        i. Very fearful
        ii. Somewhat fearful
        iii. Neutral
        iv. Not very fearful
        v. Not fearful at all
        vi. Other: _____

    c. Is the injection **better NOW than the FIRST time** you had it?
        a. Very much better
        b. Somewhat better
        c. Neutral
        d. Somewhat worse
        e. Much worse
        f. How so? _____

10. What does the **injection do**?

_____

11. What are **your concerns** regarding your eye condition? *Circle all that apply*
    a. Blindness
    b. To find a cure for your condition
    c. Lose of independence
    d. Have both eyes affected by the condition
    e. Having a knowledgeable physician
    f. Receiving the best treatment
    g. Other: _____

12. Do you feel as if **coming** to your eye appointments is **important** to your health?
    a. Yes
    b. No
    c. Do not know

13. Do you feel as if you **understand your eye condition better know than before?**
    a. Yes
    b. No
    c. Do not know
    d. Other: _____

14. Do you **want more information** about your eye condition?
    a. Yes
    b. No
    c. Do not know
    d. If no, **why not?** _____
    *e.* If yes, **from whom do you want the info**: *Circle ALL that apply*
        i. Online
        ii. Information pamphlets
        iii. One-on-one discussions with:
            1. Physician
            2. Resident
            3. Technician
        iv. Do not know
        v. Other: _____

15. How **do you get** to the Yale Eye Center? *Circle ALL that apply*
    a. Walk
    b. Drive self
    c. Spouse drives
    d. Child / children drive

e. Friend drives
f. Bus
g. Medical (free) transportation
h. Paid driver
i. Other: _____

16. Do you have any **issues** with your **transportation**?
    a. Yes
    b. No
    c. If yes, explain: _____

17. Were there **financial restraints that altered the care** you received?
    a. **Previously**?
        i. Yes
        ii. No
        iii. If yes, explain:

        _____

    b. **Currently**?
        i. Yes
        ii. No
        iii. If yes, explain:

        _____

18. Have you ever **missed or avoided** an appointment?
    a. Yes
    b. No
    c. Do not remember
    d. *If no, proceed to next question.* If yes, why?
        i. Fear of pear
            1. Yes, explain: _____
            2. No
        ii. Transportation issues
            1. Yes, explain: _____
            2. No
        iii. Wait time
            1. Yes, explain: _____
            2. No
        iv. Illness
            1. Yes, explain: _____
            2. No
        v. Other: _____

19. What is your **expectation of the medical treatment** you receive at the Yale Eye Center?

    _____

_____

a. Are you satisfied? *Circle one*
    i. Very satisfied
    ii. Satisfied
    iii. Neutral
    iv. Unsatisfied
    v. Very unsatisfied
    vi. Do not know
    vii. Anything we can do to make it better?
    _____

20. What is your **expectation of your communication** with your physician at the Yale Eye Center?

_____

---

a. Are you satisfied? *Circle one*
    i. Very satisfied
    ii. Satisfied
    iii. Neutral
    iv. Unsatisfied
    v. Very unsatisfied
    vi. Do not know
    vii. Anything we can do to make it better?
    _____

21. Do you believe that the physician is **honest** with you **about your eye condition**?
    a. Very sure
    b. Somewhat sure
    c. Neutral
    d. Somewhat unsure
    e. Very unsure
    f. Other: _____

22. How do you **feel about the how often** you come to the Retina Clinic?
    a. Very satisfied
    b. Somewhat satisfied
    c. Neutral
    d. Somewhat unsatisfied
    e. Very unsatisfied

f. Other: _____

23. Do you feel **overwhelmed** by the burden of your **eye condition**?
    a. Very much so
    b. Somewhat so
    c. Neutral
    d. Not very much
    e. Very much so
    f. Other: _____

24. Do you **fear your loss of independence** because of your **eye condition**?
    a. Very much so
    b. Somewhat so
    c. Neutral
    d. Not very much
    e. Very much so
    f. Other: _____

25. Do you have **enough time** to speak with your primary physician? And **ask your questions**? *Circle one*
    a. Yes, plenty of time to speak with doctor and ask all of my questions
    b. Yes, but I sometimes do not get to ask all of my questions
    c. Neutral
    d. No, but sometimes there is enough time
    e. No, there is never enough time and my questions never get answered
    f. No, I ask most of my questions to the residents (junior ophthalmologists or technicians)
    g. Other: _____

26. What **type of insurance** do you have? *Circle one*
    a. Uninsured
    b. Medicaid
    c. Medicare
    d. Medicare plus secondary insurance
    e. Private insurance (BCBS, Aetna, Oxford, etc)
    f. Yale Health Plan
    g. Do not know
    h. Other: _____

27. What is your **education** level?
    a. Less than high school
    b. Graduated high school
    c. Some coursework after high school
    d. Associates (two-year) degree
    e. Technical degree after high school
    f. Graduated college

g. Masters degree or beyond
h. Do not know:
i. Other: _____

28. How old are you? _____ ☺

29. What is your gender *Circle one*
    a. Male
    b. Female

30. How would you best describe yourself?
    a. Caucasian
    b. Hispanic
    c. Black
    d. Other: _____

**If you have *macular degeneration*, <u>please answer questions 31-36</u>**

**If you have *diabetes*, please <u>proceed to questions 37-43</u>**

31. Tell us **what you know** about macular degeneration: *Please describe in words*

_____

_____

32. Do you know if there are **different types** of macular degeneration? *Circle one*
    a. Yes
    b. No
    c. Do not know
    d. What are the different types?
       _____
    e. How are they different?

_____

33. Do you have **WET** macular degeneration?
    a. Yes → in ONE eye or in BOTH eyes *circle one*
    b. No
    c. Do not know

*If in WET in ONE eye only*:
d. Do you worry that your other eye will turn wet?
    a. Very worried
    b. Somewhat worried
    c. Neutral

d. Not very worried
e. Not worried at all
f. Never thought about that before

34. Do you have **DRY** macular degeneration?
    a. Yes → in ONE eye or in BOTH eyes **circle one**
    b. No
    c. Do not know

35. Do you **take PreserVision (AREDS or AREDS2**)? *Circle one*
    a. Yes
    b. No
    c. Do not know

    *If yes, answer questions **d-f**. If no, proceed to next question*

    d. Do you take it **everyday**? *Circle one*
        i. Yes
        ii. No
        iii. Do not know
        iv. If no, why?

        _____

    e. Have you ever had any **problems buying or finding** it at the store? *Circle one*
        i. Yes
        ii. No
        iii. Do knot know
        iv. If yes, why?

        _____

    f. Would you **ever not buy or take** it? *Circle one*
        i. Yes
        ii. No
        iii. Do not know
        iv. If yes, why?

        _____

        1. Because of the **cost**? *Circle one*
            a. Yes
            b. No
        2. Because of the **size** of the pill? *Circle one*
            a. Yes
            b. No
        3. Because you take **too many other pills**? *Circle one*
            a. Yes
            b. No

36. **Why** do you take **PreserVision (AREDS or AREDS2)**?
    a. For my Wet AMD

b. For my Dry AMD
c. Do not know
d. Other: _____

**If you are an AMD patient, THE END**
**THANK YOU!**

**If you have Diabetes please answer questions 30 – 35**

37. Do you know **what diabetes in the eye** is called?
    a. Yes
    b. No
    c. If yes, what? _____

38. Did you know that **diabetes in the eye can have no symptoms**?
    a. Yes
    b. No

39. What **condition** do you have? *Circle ALL that apply*
    a. Non-proliferative diabetic retinopathy (NPDR)
    b. Proliferative diabetic retinopathy (PDR)
    c. I have heard of these terms before but do not what I have
    d. I have never heard of these terms

40. Tell us **what you know about diabetic retinopathy**?

_____

_____

41. Have you had **laser** treatment? *Circle one*
    a. Yes
    b. No
    c. If yes, what is your **experience with the laser**?

_____

    a. Is laser **painful**? *Circle one*
        i. Very painful
        ii. Somewhat painful
        iii. Neutral
        iv. Not very painful
        v. Not painful at all
        vi. Do not remember

vii. Other: _____

b. It laser **fearful**? *Circle one*
   i. Very **fearful**
   ii. Somewhat **fearful**
   iii. Neutral
   iv. Not very **fearful**
   v. Not **fearful** at all
   vi. Do not remember
   vii. Other: _____

c. Is laser **better NOW than the FIRST time** you had it?
   a. Very much better
   b. Somewhat better
   c. Neutral
   d. Somewhat worse
   e. Much worse
   f. How so? _____

42. What does the laser do?

---

43. Do you know if there are different types of lasers?
   a. Yes
   b. No
   c. If yes, what are they?
      _____

**THE END**

**THANK YOU!**

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