



Low Literacy General Population People With Low Literacy

I. Introduction

- Four groups were conducted among people who were screened for low literacy.
- The low literacy groups represented members of the general population between the ages of 17 and 70.
- These groups were held in Houston, Texas, and Jackson, Mississippi.

II. Key Findings

- Participants reported getting their health information from a variety of sources, including the Internet, their family and friends, their primary care physician, health books, television shows such as *The Doctors*, and morning news shows that feature health issues.
- A few participants in each group were unclear about the difference between an ophthalmologist and an optometrist. For example, participants provided the following explanations: One is a specialist and one is not, ophthalmologists do more intensive testing than optometrists, and one is a general practitioner and one is a specialist. The following analogy was given to explain this difference: “similar to a subcontractor and contractor.”
- Participants said that their most trusted sources for health information were their primary care physicians, their optometrists, and the *Journal of the American Medical Association (JAMA)*. Participants also reported looking to optometrists, then to ophthalmologists, for information about their eyes.
- Participants noted that healthy eating and monitoring of blood pressure and glucose levels were some preventive measures for eye diseases.
- Participants reported watching family and friends struggle with diabetes, which they cited as motivation for keeping their own diabetes under control.
- Knowledge and understanding of eye diseases were very low in these groups. In two of the four groups, no one could describe any of the different eye diseases.
- Several participants said that they avoided going to eye care professionals, mainly because they did not have insurance.
- One participant reported knowing a 90-year-old woman who had never had eye problems.

- Participants reported feeling that it was important to receive more information about the symptoms of different eye diseases.

III. General Health

Self-assessment of general health

- The general health status reported by these groups varied significantly from one group to another.
- Participants in one group noted that they were in either fair or poor health.
- Most participants in the other three groups said that their health was good to excellent; a few rated their own health as fair or poor.

Frequency of healthcare professional visits

- Respondents in three of the four groups reported going to their physician at least once a year, with some going more often, particularly if they had chronic health conditions.
- Several participants in one group reported avoiding going to the physician, either because of fear/anxiety or because of not having insurance.
- A participant in one of the groups reported using home remedies instead of going to the physician.
- Those who lacked health insurance said that was a major reason they and their families did not go to healthcare professionals regularly.
 - “I work at the library, and my whole family has diabetes. We don’t have insurance, either. I have been going to the doctor’s office for years, and they have taken all my money. I went to the free clinic, and they are wonderful.”
- Several participants said that their insurance did not cover eye health.

Types of eye care professionals they see

- Participants in these groups appeared to not know the difference between optometrists and ophthalmologists.
- Two participants in one group had never heard of an ophthalmologist.
- Participants in another group provided the following explanations: One is a specialist and one is not, ophthalmologists do more intensive testing than optometrists, and one is a general practitioner and one is a specialist. The following analogy was given to explain this difference: “similar to a subcontractor and contractor.”
- Participants also had difficulty explaining the role of an optician. In one group, an optician was described as the “baby eye doctor” and “the female version of an eye doctor.”

Where they get information on health issues

- Participants reported getting their health information from a variety of sources, including the Internet, their family and friends, their primary care physician, health books, television shows (such as The Doctors and Dr. Oz), television advertisements, newspapers, magazines, and morning news shows that feature health specials.

IV. Vision

What they know about vision

- One participant reported knowing a 90-year-old woman who has never had any eye problems.
- One participant mentioned a connection among office lighting, computer screens, and deteriorating vision.
- One participant reported originally thinking that it was a myth that vision started deteriorating when a person turned 40, “until this started happening to me.”

What comes to mind when asked to describe their eyesight

- Participants noted the need for glasses to carry out their daily activities and occupations.
- Participants’ thoughts on vision included being embarrassed to wear glasses, being uncomfortable sticking anything (contacts) in their eyes, and getting headaches when not wearing glasses.

Frequency of eye exams

- In all groups, there was a wide variety of patterns for visiting eye care professionals.
- In one group, several participants noted not having had their eyes examined for an extended period of time, ranging from 30 years to five years ago. One participant in this group could not remember the last time he or she had had an eye examination.
- In another group, half of the participants had been to eye care professionals within the past two years, and the other half had not been for more than two years.
- Participants in all groups said that once every year or two was the appropriate timing for eye exams for the general population.
- Participants in all groups felt that people should have their eyes examined between once a year and every six months, depending on age. Participants also felt that eye examinations depended on affordability.
- Participants in several groups said that children, senior citizens, and those with eye problems should have their eyes examined more frequently.
- In one group, participants suggested that healthcare professionals and anyone who operated public transportation should also have their eyes examined more frequently, because their vision affected the well-being of others.

Motivation/disincentives to get eyes examined

- Participants in one group reported that they would go to an eye care professional if something was wrong.
- In all groups, motivation for going to eye care professionals included having blurred vision, experiencing headaches, having something in the eye, getting an infection, running out of contacts, and getting sties.
- In all groups, the high cost of going to eye care professionals was a major disincentive to getting eye exams on a regular basis.
- Other disincentives included lack of transportation, not having transportation after eye dilation, and lack of trust in eye care professionals.
- One participant reported that her sister used to get headaches, and when she went to the eye care professional, she found out that she was bleeding behind her eyes. She is now receiving treatment at a Veterans Administration Hospital.

- Several participants reported avoiding going to eye care professionals, mainly because they did not have insurance.

Topics discussed with eye care professionals during visits

- Most participants said that they talked only about eyesight-related things when they went to eye care professionals.
- One participant mentioned having a blind spot in his eye and, when driving, almost hitting the median. When he told his eye care professional, the response was that the participant was going blind.

Views on having eyes dilated

- Several participants in these groups did not know what “dilation” meant.
- One participant reported thinking, “It’s when the doctor blows the air in your eye.”
- Several participants in one group said that people should either not have their eyes dilated or do so only if necessary/recommended, because of the awful feeling and the wait time required after the test.
- In one group, only a few participants had previously had their eyes dilated; four participants had never heard of eye dilation.
- One participant said that people should get their eyes dilated once a year.

V. Knowledge of Eye Diseases

Knowledge of eye diseases and conditions

- Participants in these groups were familiar with cataracts, but their knowledge and understanding of other eye conditions were very limited.
- Glaucoma was a familiar word for most respondents, but few could explain it.
- One participant described glaucoma as “white spots on the brown part of the eye.”
- Participants in one group said that a symptom for both glaucoma and diabetic eye disease was “eyes running water” or draining eyes.
- A range of one to three respondents in three of the four low-literacy groups had diabetes, and they knew that their diabetes could affect their eyesight.
- Very few of the participants in these groups had heard of low vision, age-related macular degeneration, or diabetic eye disease.
- While few participants had heard of low vision, participants in one group said it sounded like “you can’t see,” “you can’t hardly see,” and “partially blind.”
- All participants in one group said there is a link between vision loss and aging.
- Participants in another group said that “age-related vision problems” referred to eyes getting older and that these problems were a natural progression of getting older.
- Five participants in one group felt that they had age-related vision problems.
- Vision loss during aging was seen to be caused by one’s circumstances, lifestyle, and diabetes.

Prevention and management of eye diseases and conditions

- Participants in one group said that healthy eating and monitoring of blood pressure and sugar levels were among the preventive measures for eye diseases.
- In one group, participants who had diabetes said that watching family and friends struggle with diabetes was motivation for keeping diabetes under control.

- Participants reported that factors that encourage people with diabetes to keep their diabetes under control included loss of vision, reduced energy level, and the struggle that family and friends with diabetes endure.
- Participants suggested that diabetic eye disease could be prevented by seeing an optometrist, eating healthy, taking care of oneself, controlling one's diet, "closing one's eyes as much as possible," resting, and not being in front of the computer screen for more than 30 minutes before looking away to rest the eyes.
- Most participants said that diabetic eye disease could be prevented.
- One participant reported knowing "the amount of sugar consumed affected diabetes, which then affected one's vision."
- Most participants were familiar with the disease because they knew a friend or family member who had the disease.
- Participants reported that prevention of glaucoma included having eye surgery, smoking marijuana, eating lots of carrots, and watching blood pressure levels.
- Participants said those at higher risk for glaucoma included elderly people and men.

VI. Health Information Preferences

Most trusted sources of health information

- Participants said their most trusted sources for health information were their primary care physician, their family and friends, local news, word of mouth, the Internet, and advertising.
- For information specifically about eyes, one group mentioned their optometrist and *JAMA*. Participants in this group also said they would look to optometrists rather than ophthalmologists for information about their eyes.
- A participant in one group said that he listens to what older people tell him he should or shouldn't do for his health.

Level of comfort in communicating with primary care physicians

- Some participants noted being uncomfortable talking with physicians in general; others noted being uncomfortable talking about embarrassing things with physicians.
- Those who said they were comfortable talking with their physicians also discussed the importance of telling physicians the whole situation, so a person could be treated for the whole problem, not just part of the problem.
- Participants in one group said that sometimes the physician won't offer materials or additional information, but that it was also the patient's responsibility to ask for things for their own health.

Level of comfort in communicating with eye care professionals

- Some participants noted being comfortable with their eye care professionals, while others reported not being as comfortable with their eye care professionals. When they have difficulty communicating with their eye care professionals, participants said they voice their concerns, see another one, or expect to not spend 30 minutes with eye care professionals because of their caseload.
- Participants reported feeling that eye care professionals should explain symptoms to their patients in a way that patients could understand eye diseases.
- Participants said they want to understand everything eye care professionals are saying; that is, they want information explained to them in plain language.

Types of information regarding eyesight/vision they have looked for

- None of the participants noted having previously looked for any information regarding eye health or disease.
- Participants reported having seen ads for glaucoma prevention medication on television, glasses commercials, advertising for LASIK surgery, and magazine articles.

Recommendations for access to information

- Participants reported that one way of getting eye information was going to Walmart and speaking with someone who wore glasses, because they reasoned that person had gone to an eye care professional.
- Participants said that they would like to have the following information about vision:
 - Symptoms of different eye diseases.
 - Age-related eye issues.
 - Eye care.
 - Information about each eye part.
 - A checklist for their eyes.
 - How to prevent astigmatism.
 - How to prevent eye diseases.
 - Eye exercises.
 - Comparison between healthy and diseased eyes.
 - Bullet points about age and vision that speak directly to them.
 - Free eye exams with a corresponding prescription.
 - Comparison of blurry and clear print in a magazine.
- Participants would like to receive vision information via direct mail or e-mail that uses large print, pictures, or diagrams.
- Others said that if they needed information, they would Google it, go to the library, or ask their healthcare professional.

VII. Summary

“One thing” that the National Eye Institute (NEI) could do for people concerning vision

- Raise eye health awareness:
 - Advertise more.
 - Make a commercial on vision (one participant suggested, “If they had a funny commercial ...”).
 - Conduct more focus groups.
 - Work with media outlets.
 - Hand out fliers.
 - Develop a billboard.
 - Develop an eye health checklist.
- Provide products and services:
 - Provide a free clinic where people can receive free information and care about their eyes.
 - Provide free eye exams.
 - Pay for eye exams and glasses.
 - Improve Medicaid coverage.

- Provide an eye exam trailer where people could get their eyes examined.