Eye health knowledge and information preferences of people at risk for glaucoma: Results of nationwide focus groups
Today’s presenters

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Glaucoma today

- Leading cause of vision loss and blindness.
- More than 2 million people affected.
- Half do not know they have the disease.
- People at higher risk:
  - African Americans over age 40
  - Everyone over age 60, especially Mexican Americans
  - People with a family history
What is glaucoma?

- Classified as a group of diseases.
- Damages the optic nerve.
- Can cause permanent vision loss if left untreated.
What causes glaucoma?

- Slow fluid drainage.
- Pressure builds up and damages the optic nerve.
- Optic nerve damage can occur at different pressure levels for different people.
Preventing vision loss

- People at risk for glaucoma should have a comprehensive dilated eye exam every one to two years.
- Glaucoma has no early warning signs or symptoms.
- Glaucoma can be treated through medications or surgery.
Methodology

- A total of 108 focus groups was coordinated.
- Eleven cities across the United States.
- Participants ranged in age from 18 to 70 years old.
- Participants included African Americans, Whites, and Hispanics/Latinos.
- Each group had 8–12 participants; 90 minute sessions.
The surveyed

Spanish-speaking

English-speaking

Older Adults

African Americans

Hispanics/Latinos

Caucasians

Have misconceptions about causes and risk factors

Desire more information

Do not know effective treatments are available
Purpose of the focus groups

• Gather information from people at higher risk for glaucoma on the following:
  – Perception of the importance of eye health
  – Knowledge of glaucoma
  – Sources of eye health information
  – Health information preferences
Eye health

- Participants stated that vision is taken for granted until problems occur:
  - “I’m a procrastinator. If it isn’t broke, I’m not going to try to fix it.”
  - “People usually delay [getting an eye exam] and don’t make it a priority.”

- Participants stated that vision gets worse over time.

- Participants’ concerns about eye health included:
  - Getting glaucoma
  - Experiencing vision loss
  - Going blind
Eye health practices

• The majority reported having their eyes dilated at least once a year.

• Participants’ motivations for getting an eye exam were:
  – Changes in vision
  – Insurance status
  – Family history
  – Doctors’ instructions

• Participants stated that cost is a factor in receipt of care.
Knowledge

• Participants were familiar with:
  – The term “glaucoma.”
  – Who is at higher risk for getting glaucoma.

• Participants were less familiar with:
  – The disease, diagnosis, treatment, and long-term effects of glaucoma.
  – The fact that vision loss can be prevented with early detection, proper treatment, and regular eye appointments.
Their “symptoms”

- Loss of sight
- Pain that feels like “a punch with an ice pick”
- Fluid buildup
- Tearing
- Tunnel vision
- Stars in field of vision
- Increased pressure in the back of the eye
- Headaches
- Dizziness
- Redness
- Blurred, cloudy, or hazy vision
Their prevention methods

- Avoiding harsh temperature changes
- Exercising your eyes
  - Not watching so much television
- Taking out contact lenses before going to sleep
- Cleaning eyes internally
- Taking vitamins
  - Restricting sweets
- Eating carrots
  - Using glasses
  - Lowering blood pressure
  - Resting your sight
- Not using the computer so much
- Not staring at the sun
- Using protective glasses
What they said

Perceptions

• “People, society as a whole, look at glaucoma as an older person’s disease, but babies can have glaucoma, and that’s something we failed to see.”

• “Glaucoma is almost a fact of life for people with high blood pressure and diabetes.”

• “It gets worse and worse. There is no cure for it. Once you develop glaucoma, you just have it.”
What they said
Perceptions

• “I try to ask my husband if he can tell me how much and what he can see, but he tells me he can’t describe it.”
• “Us diabetics have a tendency to suffer of that [glaucoma] when we don’t pay attention to our food, exercise, and proper medicine.”
• “Important conditions like cancer, diabetes, and AIDS capture the media, but there’s nothing on the eyes.”
• “I thought glaucoma and cataracts were pretty much the same. It really didn’t have an effect on me. That’s one reason why I never thought about it.”
Key findings

- Identified their ethnicity as a risk factor for glaucoma.
- Identified the high cost of glasses and eye care as an obstacle to receiving eye care.
- Noted that the motivation of eye care professionals is to get patients to spend money.
- Have seen little in the media about eye care and glaucoma.
Their suggestions

- Work with Medicare to pay for eye exams.
- Provide more information through TV, magazines, or a DVD.
- Develop a multilingual website.
- Partner with drug stores, ophthalmologists, and optometrists.
- Present information that people, regardless of age, should have their eyes checked.
- Schedule a national eye care day.
- Spend more money for research.
Whom do they trust?
Sources of eye health information

- Physicians
- Family members
- Friends
- Dr. Oz
- CNN (Dr. Gupta)

- WebMD
- AskaNurse.com
- Arthritis Today
- Men’s Health
- Discovery Health Channel
Opportunities for increasing eye health knowledge

- Increase public awareness and education activities.
- Provide more concise information in a variety of formats, including:
  - Fact sheets
  - Brochures/pamphlets
  - Ads in doctors’ offices and state departments of motor vehicles
  - Magazines
  - Public service announcements
  - Social media
Opportunities for increasing eye health knowledge

• Improve doctor/patient communication:
  – Doctors taking time to listen and not rushing patients.
  – Doctors asking the right questions.
  – Patients advocating for themselves.
  – Patients making a list of their questions.

• Conduct outreach activities at churches, health fairs, and other community settings.

• Develop mobile units to conduct vision screenings.
Glaucoma resources

http://www.nei.nih.gov/NEHEP
Keep Vision in Your Future: Glaucoma Toolkit

• Designed to help you increase awareness about glaucoma.
• Includes a PowerPoint presentation, speaker's guide, participant handouts, and more.
• Visit the Toolkit Web page: http://www.nei.nih.gov/GlaucomaToolkit
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Glaucoma is more common in African Americans than in Whites.

True
False

www.nei.nih.gov/healthyeyes

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National Eye Institute - Glaucoma

www.nei.nih.gov/healthyeyes

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http://www.nei.nih.gov/nehep

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