Preventing vision loss and blindness:  
What people with diabetes know about their eyes  
Results from nationwide focus groups
Today’s presenters

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Diabetes today

- 26 million people affected.
- 79 million with pre-diabetes.
- All people with diabetes at risk for diabetic eye disease.
- Diabetic eye disease is a serious complication of diabetes.
  - Leading cause of vision loss and blindness in adults ages 20-74.
What is diabetic eye disease?

**DIABETIC RETINOPATHY**
- Most common form of diabetic eye disease.
- Diabetes damages the blood vessels in the retina, the light-sensitive tissue at the back of the eye.

**CATARACT**
- Clouding of the lens of the eye.

**GLAUCOMA**
- Increase in fluid pressure inside the eye that leads to optic nerve damage and loss of vision.
Preventing vision loss

- People with diabetes should have a comprehensive dilated eye exam at least once a year.
- No early warning signs or symptoms.
- 90% of vision loss can be prevented.
- In addition to eye exams, keep your health on TRACK:
Take your medications.
Reach and maintain a healthy weight.
Add physical activity to your daily routine.
Control your blood sugar, blood pressure, and cholesterol.
Kick the smoking habit.
Purpose of the focus groups

Gather information from people with diabetes on the following:

- Importance of eye health
- Knowledge of diabetic eye disease
- Sources of eye health information
- Health information preferences
The surveyed

**Ages 18-70**

- Spanish-speaking
- People with diabetes
- Visited doctors yearly
- English-speaking
- Hispanics/Latinos
- Caucasians
- Visited doctors every 3 months

- Cleveland, OH
- Houston, TX
- Atlanta, GA
- Washington, DC
- Miami, FL

**National Eye Institute**

**National Eye Health Education Program**
Eye health

• Participants aware of impact of diabetes on their vision:
  • Blurry vision
  • Deterioration of vision over time
  • Blindness
  • Intense light
  • Headaches
  • Tunnel vision and dimness
Knowledge

- Doctors direct in telling risk of losing vision due to diabetes.
- Lack of familiarity with the term “diabetic eye disease.”
- Many recognize is a serious health problem that needs to be treated.
Their “symptoms”

- Reduced field of vision
- Flashing lights
- Floaters
- Tunnel vision
- Headaches
- Blindness
- Blurred Vision
Prevention

Awareness
Some knowledge
Understanding
Distrust

• “Diabetic eye disease cannot be prevented, just treated.”
• “Diabetic eye disease can be treated by cooperation between ophthalmologists and primary care physicians.”
• “It can be prevented with drops, surgery, medication controls, and diet.”
• “Drink lots of water or have a water purifier.”
• “Not sure if certain tests are necessary.”
• “Getting a second opinion if I don’t like results.”
Treatment

KNOWLEDGE

• Awareness of treatment options.
• Awareness it can be treated.
• A balancing act.

BELIEFS

• No treatment options for diabetic eye disease.
• Blindness inevitable.
• “At eye exam, doctor can’t detect disease. I notice if vision is blurrier.”
What they said

Biggest concerns

• “Losing eye sight.”
• “Not knowing if it’s going to get worse.”
• “Possibility of blindness.”
• “Lack of vision without glasses.”
• “If I can’t see, I can’t work.”
• “Independence and mobility.”
What they said
Reasons to keep diabetes under control

• “Don't want to lose my vision.”
• “I just want to live.”
• “The possibility of what can happen; get all the bad things down.”
• “My general health, vision.”
• “Have a "normal life".”
• “Knowing people who have had eye problems.”
• “Being self-sufficient.”
Key findings from diabetes groups

Caucasian
- Awareness of relationship between diabetes and eye health, but no familiarity with term “diabetic eye disease.”
- More emphasis on vision in diabetes education programs, materials.
- Information from doctors and family members in health professions.
- Better communication between health providers to improve health care for patients.

Spanish-speaking H/L
- Onset of diabetes a wake-up call for many.
- Little knowledge of diabetic eye disease.
- Information from doctors and others with diabetes.
- Some comfort with doctors.
- Some discrimination by non-Hispanic doctors.

African American
- Vision of high importance.
- Lack of knowledge regarding consequences of diabetes and eye health.
- Some familiarity with terms “diabetic eye disease” and “diabetic retinopathy.”
- General perception that diabetic eye disease can’t be prevented.
- Cost of eye care of concern.
Their suggestions

Caucasian
- More education on vision and latest treatments for eye diseases.
- Importance of a good doctor/patient relationship for managing diabetes.
- Decreased wait time and “whole ordeal” of dilating, waiting, then waiting for the eyes to get back to normal.
- Visual aids on what happens to eyes after diabetes to help explain the importance of managing the condition.

Spanish-speaking H/L
- More affordable eye care services.
- Improvement in way eye care professionals communicate with patients.
- Appreciation of doctors who understand them.
- Information on diabetes through video and print materials helpful when newly diagnosed.

African American
- Better doctor/patient relationship, from extra time with patients to interest and followup.
- More information on eye health and education.
- Print materials.
- Non-traditional outreach, like pharmacies.
- Community events and coordinated efforts with diabetes groups.
Whom do they trust?
Sources of eye health information

- Physicians
- Diabetes specialists
- Newsletters from insurance companies
- Google
- Friends and family with diabetes
- Videos at doctors’ offices
- Supermarkets
- Nurses
- Ophthalmologists
- Pamphlets
- Magazines
- Radio
- WebMD
Where do they seek information?
Their health information preferences

- Doctors’ offices
- Support groups
- *Diabetic Living*
- National Public Radio
- American Diabetes Association
- Church
- Magazines
- Internet
  - Google, Mayo Clinic, WebMD, Wikipedia
- Information in Spanish
- Dr. Oz show
Opportunities for increasing eye health knowledge

- More eye health information from doctors.
  - More patient materials, videos.
  - Newsletters.
  - E-mails.
  - Reminders, calls.
- Facilitation of behavior change and advocacy through participant knowledge.
  - Information in the hands of the community.
  - Brochures.
  - Resources in Spanish.
Common threads

- Vision taken for granted unless something goes wrong.
- Diabetes a major impetus for taking better care of self and eyes.
- Most positive about relationship with doctors.
Common threads (cont.)

• Lack of awareness/understanding of diabetic eye disease.
• Interest, concern about eye health and desire to have eyes examined.
• Importance of repeated messages about seeing an eye doctor to people with diabetes.
Diabetic eye disease resources

www.nei.nih.gov/NEHEP
Stay engaged with NEHEP!

Publish our widget on your site

Use our YouTube videos
Questions?

For more resources, please visit www.nei.nih.gov/nehep and www.nei.nih.gov/diabetes

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