



INVESTIGATING AVOIDABLE BLINDNESS IN OREGON

Stephanie Lam, Tasha Zaback, Joan Randall,
Teresa Field, & Mitch Brinks



Oregon Commission for the Blind (OCB) Mission

Empower Oregonians who are Blind to Fully Engage in life

OREGON
COMMISSION
FOR THE
BLIND

OHSU Casey Eye Institute Casey Outreach Research Program:

To partner with communities, academic, and professional organizations to advance the understanding of eye disease and to develop effective programs to reduce avoidable blindness in Oregon.



Together we joined forces to...

...evaluate the state of Oregon's blind population with a three pronged approach which:

1. Using registry data, report on the **incidence of blindness** in the state of Oregon from 1961-2017
2. Examine the **gaps in care** before and after blindness
3. Investigate **strategies to prevent** avoidable blindness in Oregon.

Our focus today..

2. *Examine the gaps in care before and after blindness ([interviews](#))*
3. *Investigate strategies to prevent avoidable blindness in Oregon ([focus groups](#))*

Why is this important?

- Prevalence of blindness is expected to double over the next several decades. ^{1,2}
- Blindness causes deterioration in quality of life, wealth status, and independence, having enormous impacts on patients, families, and communities. ³⁻⁶
- Combined costs of medical care and workforce losses from vision impairment in the U.S. amounts to 139 billion dollars a year. ⁷

Importance of interview – Step 1

- Most studies on eye care access do not incorporate the patient experience navigating the vision care system to understand how the complexities of accessing vision care affect patients' abilities to meet their needs. Through their voice, we hope that missed opportunities for care can be addressed at multiple levels of interaction.
 - *The people who have primary experiences are the experts*
 - *Gaps in primary voices of these experts in the literature*

Methods

- For this project, we conducted semi-structured telephone interviews using closed and open-ended questions with Oregon residents with blindness recruited by the Oregon Commission for the Blind
 - *Convenience sampling was conducted through volunteer counselors and teachers to identify adult persons with blindness due to macular degeneration, glaucoma, and diabetic retinopathy from both urban and rural locations*
 - *An opt-in informed consent was mailed to potential participants who mailed back signed forms if they agreed to participate*
- Questions were around historical views on events and experiences while interacting with health care resources during their course of vision loss to blindness

Qualitative analysis

- Interviews were conducted by one researchers
- Thematic saturation was reached at 28 participants
- The data were coded thematically and analyzed for emerging themes utilizing a grounded theory approach
- 2 independent researchers
 1. Preliminary review of data
 2. Developed list of emerging themes independently
 3. Discuss and refine themes into codes
 4. Coded independently
 5. Met and discuss coding of transcripts
 6. Recoded and discussed until discrepancies were resolved
- Results were reviewed by original interviewer

Results: Categorical Data

<i>Participant Characteristics (n=28)</i>	<i>n (%)</i>
Age	
40-59	5 (17.9)
60-69	6 (21.4)
70-79	7 (25.0)
80+	10 (35.7)
Gender	
Female	16 (57.1)
Male	12 (42.9)
Race	
American Indian or Alaska Native	1 (3.6)
Black or African American	1 (3.6)
Native Hawaiian or other Pacific Islander	1 (3.6)
White	25 (89.3)

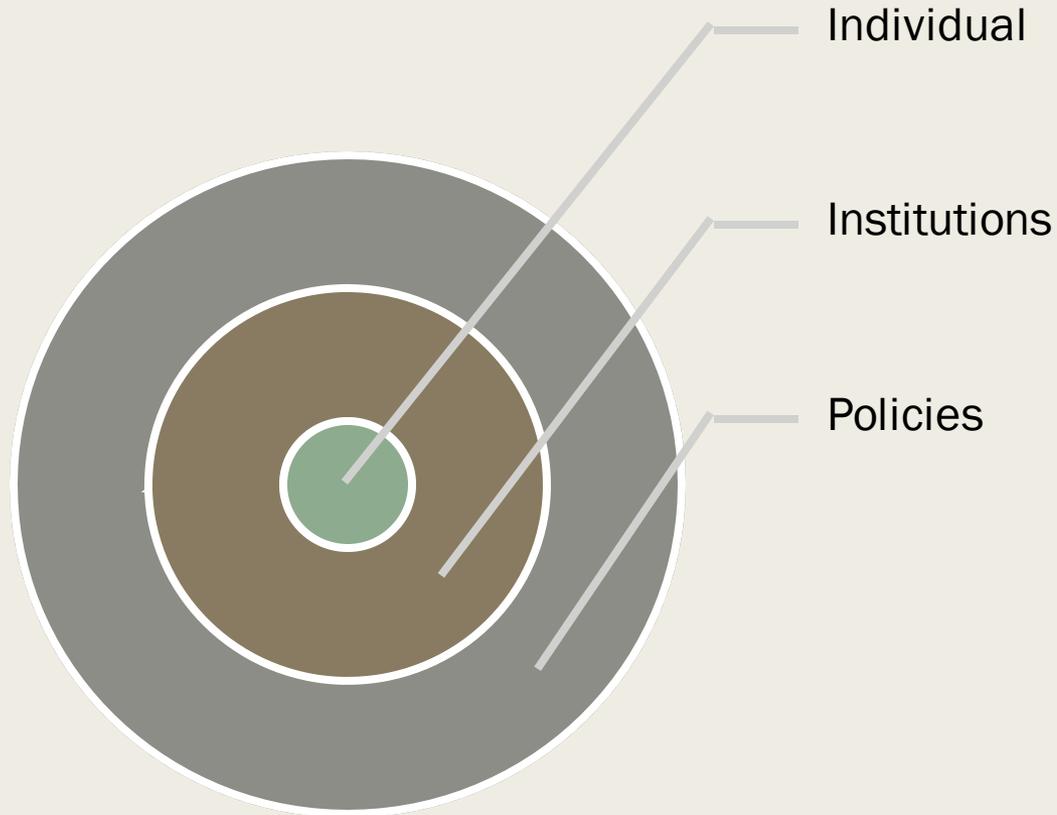
Results: Categorical Data

<i>Participant Characteristics (n=28)</i>	<i>n (%)</i>
Education Level	
Completed some high school	4 (14.3)
Completed high school	4 (14.3)
Completed some college	11 (39.3)
Graduated from college	6 (21.4)
Graduate degree	3 (10.7)
Household income at onset of vision loss	
Less than \$20,000	9 (32.1)
\$20,000 to \$34,999	7 (25.0)
\$35,000 to \$49,999	6 (21.4)
\$50,000 to \$74,999	2 (7.1)
\$75,000 to \$99,999	2 (7.1)
\$100,000 to \$149,999	1 (3.6)
\$150,000 or more	1 (3.6)

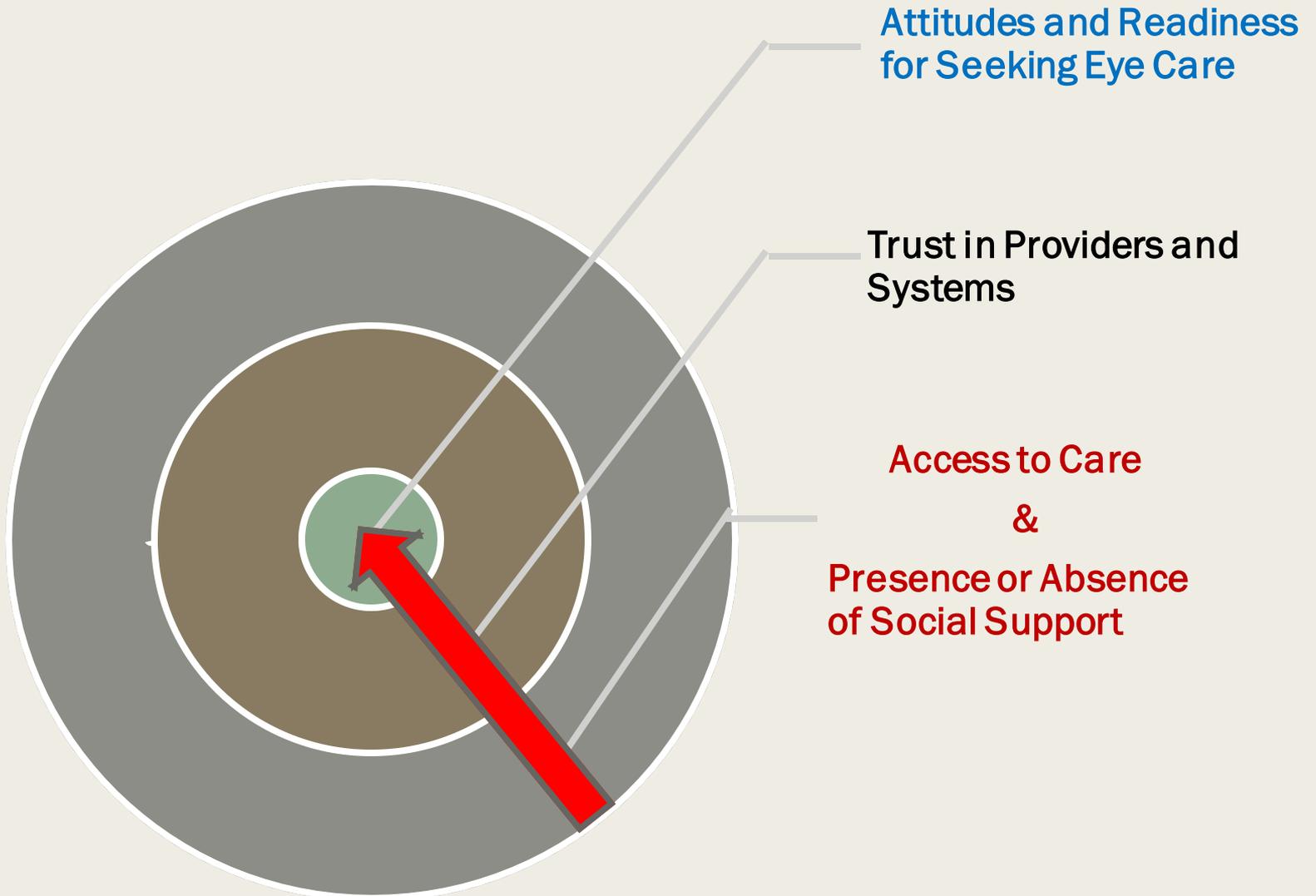
Results: Categorical Data

<i>Participant Characteristics (n=28)</i>	<i>n (%)</i>
Income affected by vision loss	
Yes	10 (35.7)
No	18 (64.2)
Urban or Rural	
Rural	15 (53.6)
Urban	13 (46.4)
Diagnosis	
Macular Degeneration	16 (57.1)
Glaucoma	4 (14.3)
Diabetic Retinopathy	4 (14.3)
Multiple diagnoses	3 (10.7)
Other	1 (3.6)

Thinking about codes in Levels



Themes



Main Themes	Sub-themes
<p>Access to Care: Reasons why patients access or delay getting eye care.</p>	<ul style="list-style-type: none"> - Availability of eye care providers - Insurance/Costs - Patient – Medical systems interaction
<p>Trust in Providers and Systems: Either negative or positive comments about trust</p>	
<p>Attitudes and Readiness for Seeking Eye Care: Attitudes, behaviors, and feelings in seeking eye care</p>	<ul style="list-style-type: none"> - Awareness - Prioritizing - Denial
<p>Presence or Absence of Social Support: This code is used to describe the person's ...Access to social services/support groups, family support, literature, websites, etc.</p>	

THEMES, DEFINITION, AND NARRATIVES



Access to Care

Reasons why patients access or delay getting eye care.

Subtheme

Availability of Eye care providers

“I got an invitation to one [referring to a clinical trial] in Portland. But I couldn’t go because I can’t drive. I can’t get anybody to take me there. So, I didn’t do that.”

“I would have had to drive three hundred miles, one way.... My first treatment was in Portland because there were no doctors in Bend at that time. And then in the winter time we have to take the people mover [transportation services] to Bend to the doctors.”

Access to Care

Reasons why patients access or delay getting eye care.

Subtheme

Insurance/Costs

“Medicare pays for the glasses. But they wouldn’t pay for the refraction.”

[Participant describes her interaction with her doctor] “Is this the caused from my lymphedema? He [Participant’s doctor] goes, if I write down lymphedema, I don’t get paid. So I’m going to say it’s caused from your diabetes. Are you on board here?”

Access to Care

Reasons why patients access or delay getting eye care.

Subtheme

Patient-medical systems
interaction

Different layers to fully accessing
care/medical system/providers.
Patients perceived ability to
navigate the healthcare system.
System barriers and facilitators.

“That was one of the biggest concerns ...They basically let me out the back door. Or I walked out the back door. They didn’t guide me at all with vision options. And that’s one of my complaints. And when I talked to my comrades in the blind community, the same thing. If they can’t salvage the sight, they lose interest or lose income. That’s the cold way to do it.”

“...I was just exasperated because they won’t address the left eye. I’m getting older, not getting any younger. And I’m tired of not being able to see. I called and asked to speak to the doctor that removed the cataract. And do you know what they said? You can’t talk to him. I said, excuse me? He’s my doctor. No, he’s not your retina specialist. It needs to go through him. And I said, no. I need to talk to the guy that removed the cataract. She goes, well, I can’t let you do that. Twice, I tried to call. And they won’t let me talk to him. Now, that doesn’t sound right. Why don’t they want me to talk to him? “

Trust in Providers and Systems

Either negative or positive comments about trust

“ I’ve been askin’ retina consultants for years. I can’t remember now how long I’ve been going there, probably 7 or 8 years. And the first doctors,...wouldn’t directly give me an answer. Was I losing my sight or not?”

“Well, some of the VA doctors, of course...Almost all the doctors there at the VA are from the health site center. And a lot of them I don’t trust at all. Just because, you know, they tell me one thing and they do another.”

Attitudes and readiness for Seeking Eye Care

Attitudes, behaviors, and feelings in seeking eye care

Subtheme

Awareness

This includes knowledge of recommendation of eye health exams. Includes knowledge gap

“No. Before that I never really went [referring to before experiencing any symptoms]. I didn’t need glasses. I never had trouble seeing.”

Attitudes and readiness for Seeking Eye Care

Attitudes, behaviors, and feelings in seeking eye care

Subtheme

Prioritizing

Action oriented (Individual personal responsibility level)
How quickly a person decides to take action on recommendation for eye care and how they decide to prioritize eye health.

“Until I lost my eyesight it was inconsequential.
When I lost my eyesight it was extremely important.”

Before that I never really when. I didn't need glasses. I never had trouble seeing....[Then] one day, and this came upon me. I just, everything was blurry. And I wondered why. And I thought, oh, I'm just tired. So I guess I'll go upstairs. Because I was working in my flower garden. And then I thought, wait a minute, this is not right. Something is wrong. Everything is so fuzzy. So I just got in the car and drove myself to the eye doctor. And then she checked them and said that's where I had this. They were bleeding in the back...”

“Yeah. I did not realize how important my eyes were...take for granted I guess.”

Attitudes and readiness for Seeking Eye Care

Attitudes, behaviors, and feelings in seeking eye care

Subtheme

Denial

“It doesn’t happen to me” I don’t have anything, or I will get better on my own.
Inevitable part of aging and perceiving that everyone goes through the same thing.

“I don’t know anything that we could have done that would have made a difference. Like I said, it seemed to digress real quickly after the cataract operation. But I don’t know if it’s related or not....I’ve talked to others too that have had the same experience. So, they had the eyes operated on and wasn’t long before they got...Oh, it’s an affliction of age....And even mine, which is...which I think is related to the family history. I didn’t really [get it] fixed...I was first diagnosed at fifty”

“general stupidity-father and uncle had glaucoma, but didn’t pay attention, denial”[This person was aware of treatment related to eye problem but did not seek treatment.]

Presence or Absence of Social Support

This code is used to describe the person's ...Access to social services/support groups, family support, literature, websites, etc.

“My son does...since he's moved here he does all the cooking. Before he came back, my husband wasn't eating very much. So he was just mostly living on Ensure. And I did some. But I was, truthfully, doing a lot of fast foods. Since my son has moved back, he disapproves of so we do not have anymore TV dinners.”

“... the Commission for the Blind has been wonderful. I belong to a book club. And they send...I can mostly get all of the titles through the talking (books).”

“Nobody lives with me. I have a friend, a neighbor. She helps me, when she can... I try not to have to go anywhere or do anything, unless it's absolutely necessary. So I'm basically stuck in the house all the time. And my husband, he lives at an assisted living place, so...”

Conclusions from the Interviews

- These data suggest that recognition of the importance of eye health is often achieved only after the loss of vision.
- Our findings did not indicate significant differences in awareness or recognition of the importance of eye care based on household income
- The lack of awareness and prioritization of eye care seems to be further complicated by the limited availability of eye care providers, cost of care, and difficulties navigating insurance for eye health - and medical systems-
- Many people reported not seeking recommended eye care due to a lack of vision insurance or allowable expense on medical insurance

To be continued...

There is a need to go back to the community and ask them about preventive strategies using hindsight 20/20

Focus groups – Step 2

- Focus Groups were conducted using a discussion guide developed by the research team concentrated on identifying strategies and interventions to prevent avoidable blindness in Oregon.
 - *How do they get information from healthcare systems/providers*
 - *What would they do differently if before and after being diagnosed*
 - *Recommendations for developing interventions that may help prevent people from going blind*
 - *Who and where should to target messages*

Methods

- Regional focus groups (5) ranging from 4-15 participants lasting 47-70 minutes
 - *Portland metropolitan*
 - *Willamette Valley*
 - *Oregon Coast*
 - *Southern Oregon*
 - *Eastern Oregon*
- Audiotaped, transcribed and coded by two researchers for emergent themes using Nvivo for data management

Results

Policy Advocacy	All (5) reported a need for policy changes to insurance coverage.
Health education in clinic	All (5) reported a need for health education in the clinic with ancillary staff.
Multi-media campaigns	All (5) reported a need for campaigns to build awareness of preventive eye health exams.
Help navigating systems of care	Four (4) asked that clinics refer to low vision and mental health services.
Vision health training to health care workforce	Three (3) asked that we increase the vision health knowledge base and skills of the health care work force (Primary Care Providers, Nurses, Endocrinologists)
School-based programs	Two (2) suggested school-based efforts expand their focus (beyond head start and elementary school)
Mentorship	Two (2) requested a “mentorship” program matching to other patients with the same eye disease

Strategies

Policy:

Eliminate the separation of vision insurance from health insurance

Advocate for preventive eye exams as an allowable expense

Community:

Campaigns to increase awareness of vision health and prevention broadly

School-based prevention education programming

Provider/Systems:

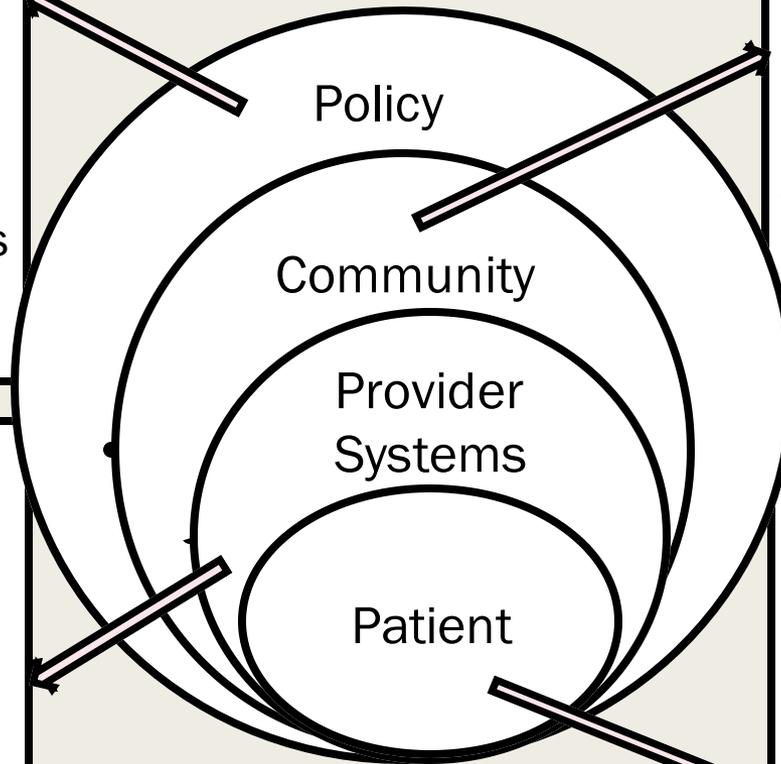
Train ancillary staff to conduct health education with patients

Vision health training to health care workforce

Patient:

Health Navigators to address gaps in care

Mentorship by partnering with organizations that support people with vision loss



Summary

- Our findings support the following recommendations:
 - 1) Address access under various insurance policies to allow for preventive eye exams
 - 2) Advocate for the integration of vision insurance with health insurance
 - 3) Increase access to programs that improve and maintain function in people with vision impairment
 - 4) Public health campaigns that promote eye health
 - 5) Provide training to a broad healthcare workforce in eye health (Primary Care Providers, Nurses, etc.)
 - 6) Provide health education and navigation services to patients

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