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**All attendees are muted. Today's session will be recorded.**

# Mental Health Implications of Blindness and Vision Loss

Steven Silverstein, Ph.D.

Departments of Psychiatry, Neuroscience, and  
Ophthalmology

Center for Retina and Brain

University of Rochester Medical Center

June 13, 2023



Northeast and Caribbean (HHS Region 2)

**MHTTC**

Mental Health Technology Transfer Center Network  
Funded by Substance Abuse and Mental Health Services Administration

**Mental Health Technology Transfer Center**  
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**Northeast and Caribbean  
Region 2**

**General Mental  
Health Workforce**

**Provider  
Wellness**

**Youth & Young  
Adult Services**

**School Mental  
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Feedback about this training will assist us in developing future trainings that are relevant to your professional needs. Therefore, your feedback counts!



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At the time of this presentation, Miriam Delphin-Rittmon served as Assistant Secretary for Mental Health and Substance Use at SAMHSA. The opinions expressed herein are the views of the speakers, and do not reflect the official position of the Department of Health and Human Services (DHHS), or SAMHSA. No official support or endorsement of DHHS, SAMHSA, for the opinions described in this presentation is intended or should be inferred.

This work is supported by grant H79SM081783 from the DHHS, SAMHSA.



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## **Question and Answers**

- Q & A will occur at the end of the call.
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The MHTTC Network uses affirming, respectful and recovery-oriented language in all activities. That language is:

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AND HOPEFUL

INCLUSIVE AND  
ACCEPTING OF  
DIVERSE CULTURES,  
GENDERS,  
PERSPECTIVES,  
AND EXPERIENCES

HEALING-CENTERED AND  
TRAUMA-RESPONSIVE

INVITING TO INDIVIDUALS  
PARTICIPATING IN THEIR  
OWN JOURNEYS

PERSON-FIRST AND  
FREE OF LABELS

NON-JUDGMENTAL AND  
AVOIDING ASSUMPTIONS

RESPECTFUL, CLEAR  
AND UNDERSTANDABLE

CONSISTENT WITH  
OUR ACTIONS,  
POLICIES, AND PRODUCTS

A woman with dark curly hair is looking out a window at a cityscape. The window is partially covered by white curtains. The background shows a blue sky with clouds and a tall building.

# 988

SUICIDE  
& CRISIS  
LIFELINE

**For people experiencing:**

- Suicide, mental health, substance use crisis
- Emotional distress
- People concerned about someone in crisis

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Substance Abuse and Mental Health  
Services Administration

# Meet Today's Presenter:



Steven Silverstein, Ph.D.

# MENTAL HEALTH IMPLICATIONS OF BLINDNESS AND VISION LOSS

Steven Silverstein, Ph.D.

Departments of Psychiatry, Neuroscience, and Ophthalmology

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# DISCLOSURE STATEMENT

- Conflicts of interest: None
- Funding:
  - National Institute of Mental Health
  - Chernowitz Medical Research Foundation
  - Patrick P. Lee Foundation
  - Accelerating Medicines Partnership

# OVERVIEW

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- Facts and findings about blindness and vision loss
- Eye basics
- Common causes of vision loss
- The limits of typical available services for addressing mental health needs
- Unmet mental health needs in people with B/VI
- Lack of available and effective MH services
- Recommendations and resources
- Conclusions



# BLINDNESS AND VISION LOSS

(DATA FROM CDC VISION HEALTH INITIATIVE WEBSITE)

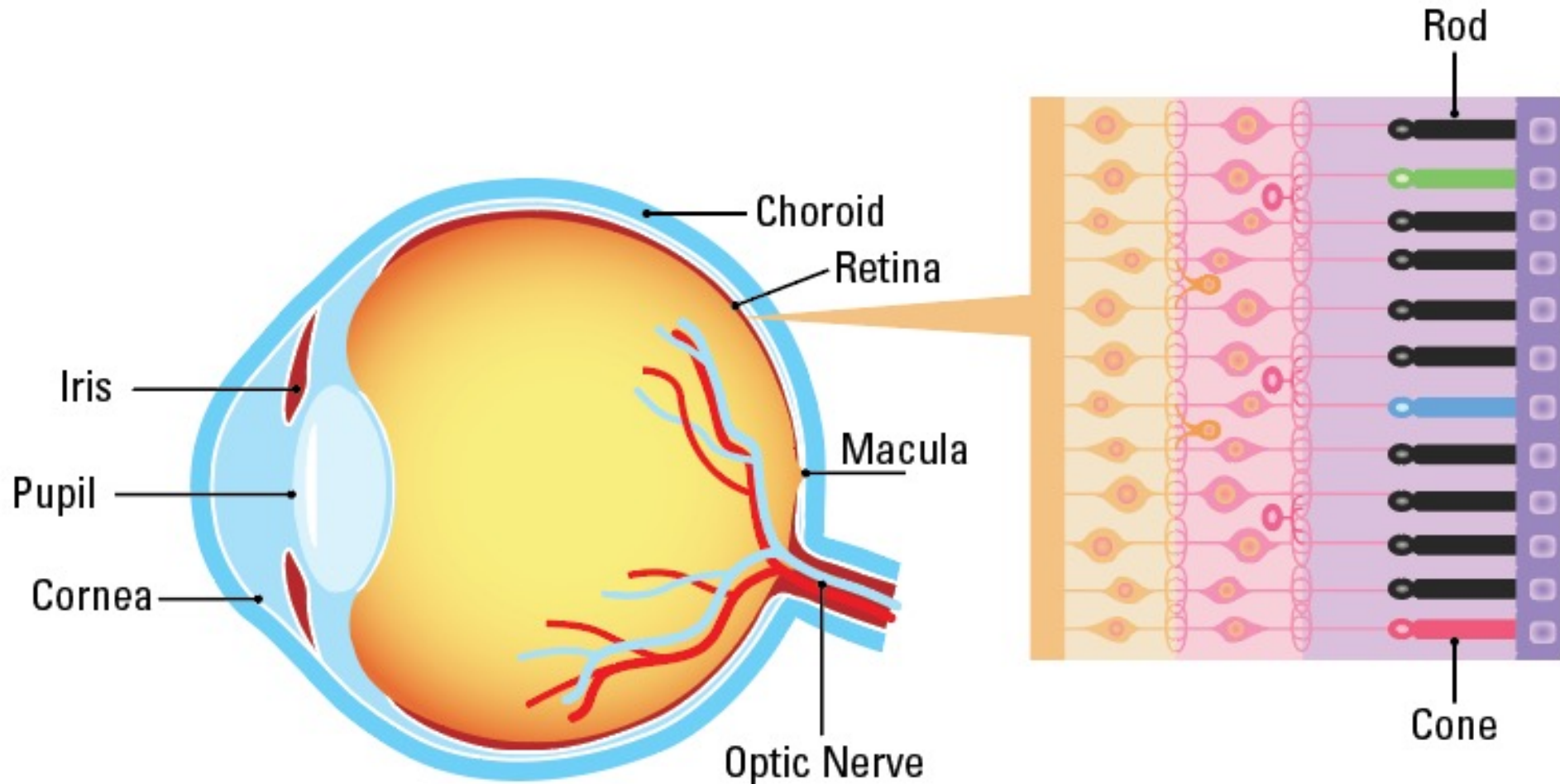
- More than 3.4 million Americans aged 40 years and older are blind (having a visual acuity of 20/200 or less or a visual field of 20 degrees or less) or visually impaired (having a visual acuity of 20/40 or less).
- Other estimates of “vision problems” range as high as 21 million.
- 80 million Americans have potentially blinding eye diseases.
- The major causes of vision loss are cataracts, age-related macular degeneration, diabetic retinopathy, and glaucoma.

# MORE FINDINGS ON VISION LOSS

- People with vision loss are more likely to experience:
  - Depression
  - Diabetes
  - Hearing impairment
  - Stroke
  - Falls
  - Cognitive decline
  - Premature death
- Decreased ability to see is associated with reduced ability to:
  - Drive
  - Read
  - Manage finances
  - Travel
- The cost of vision loss, including direct costs and lost productivity, is estimated to exceed \$35 billion (Rein, Zhang, Wirth, et al., 2006)

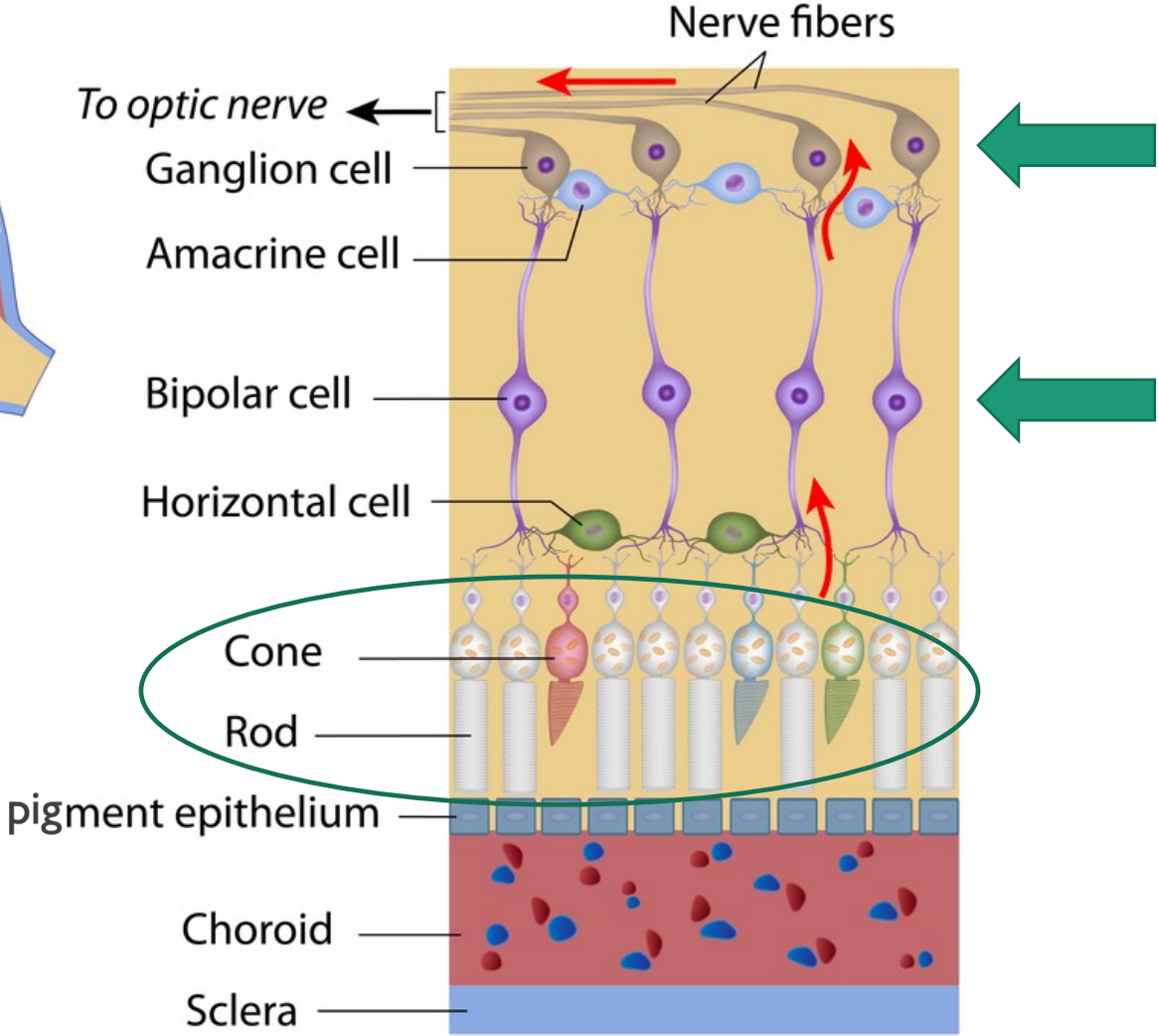
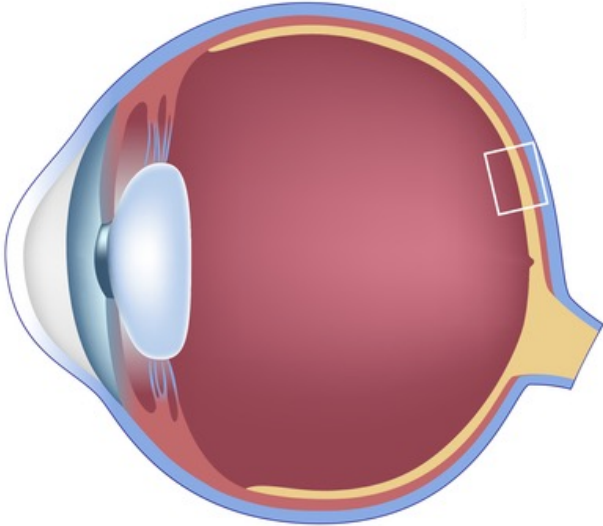
# STRUCTURES OF THE EYE

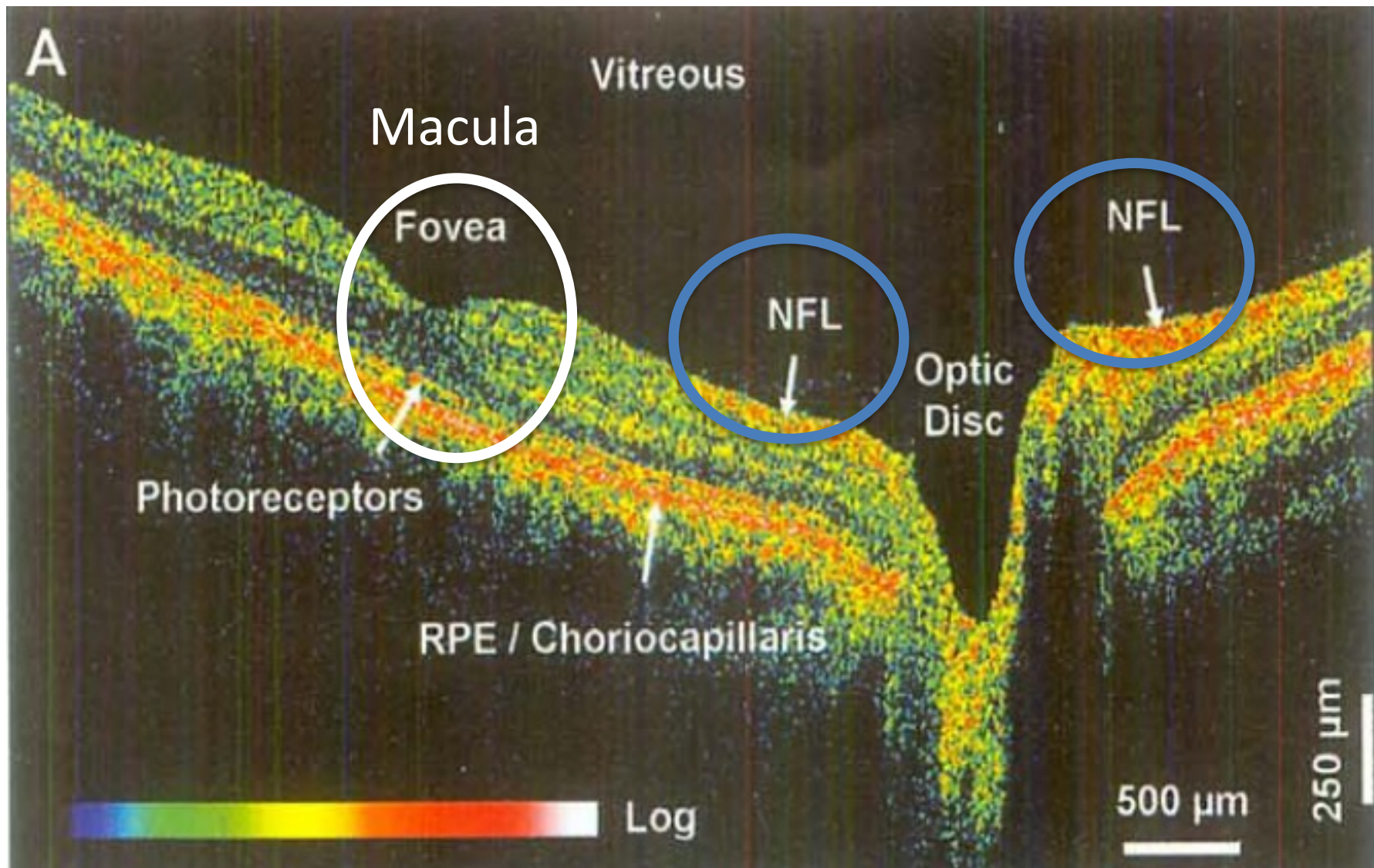
(IMAGE FROM PREVENT BLINDNESS WEBSITE)



# Structure of the Retina

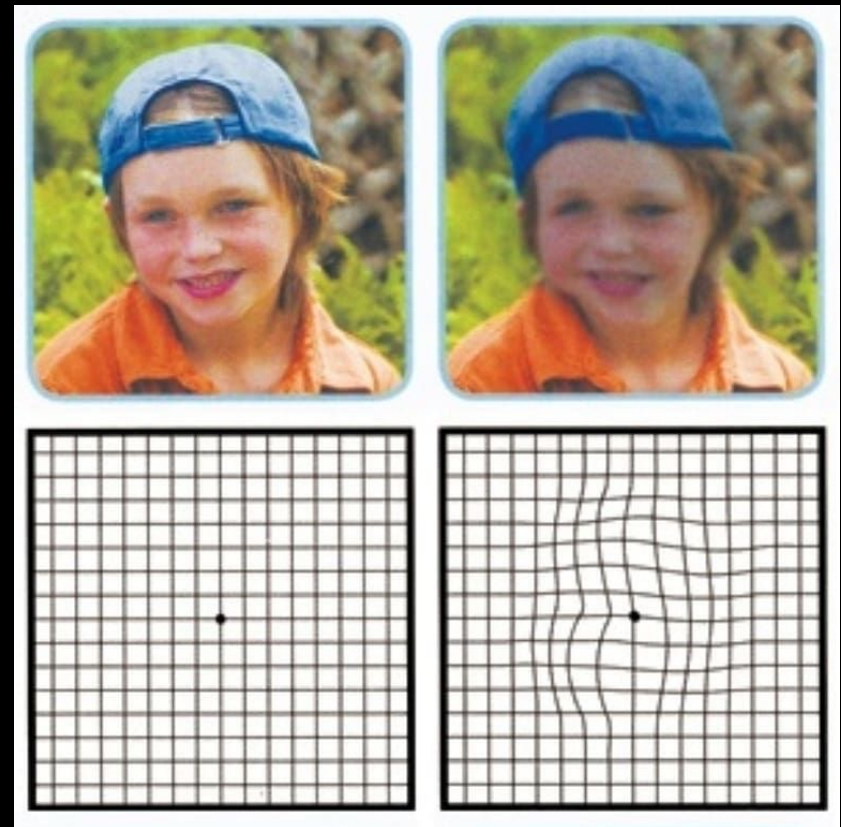
Light





# MACULAR DEGENERATION

- Two types
- Wet or neovascular/exudative AMD involves the growth of new blood vessels under the macula that could potentially leak
- Dry AMD or pure geographic atrophy involves degeneration of the RPE in the foveal center, causing scars in the foveal area and a loss of central vision (CDC Vision Health Initiative)



# MACULAR DEGENERATION

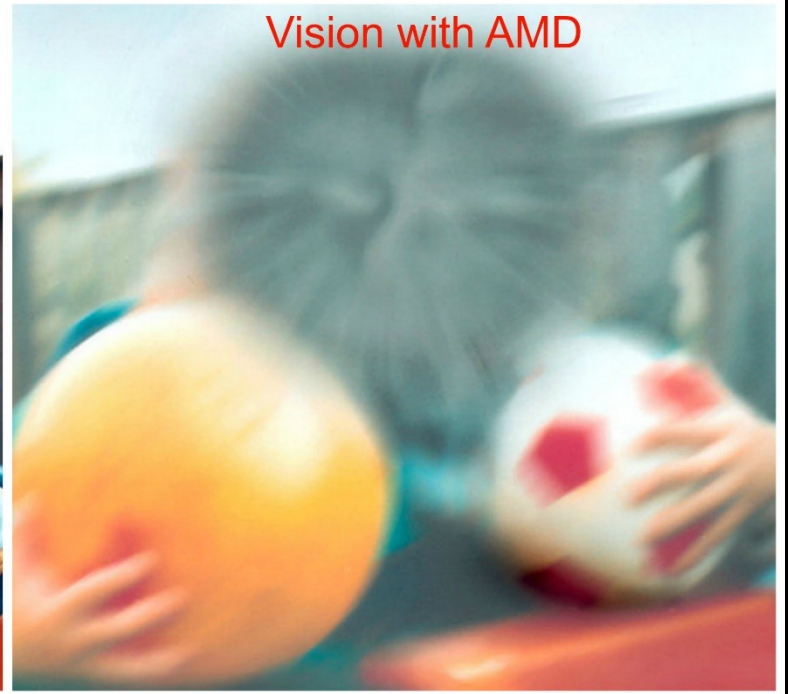


# MACULAR DEGENERATION

Normal Vision



Vision with AMD





AN INHERITED FORM OF MACULAR  
DEGENERATION THAT TYPICALLY  
BEGINS IN CHILDHOOD OR  
ADOLESCENCE IS CALLED  
**STARGARDT'S DISEASE**



# RETINITIS PIGMENTOSA (RP)

INHERITED EYE DISEASES THAT CAUSE BREAKDOWN IN  
ROD AND CONE PHOTORECEPTORS



**NORMAL VIEW**



**VIEW WITH  
RETINITIS PIGMENTOSA**

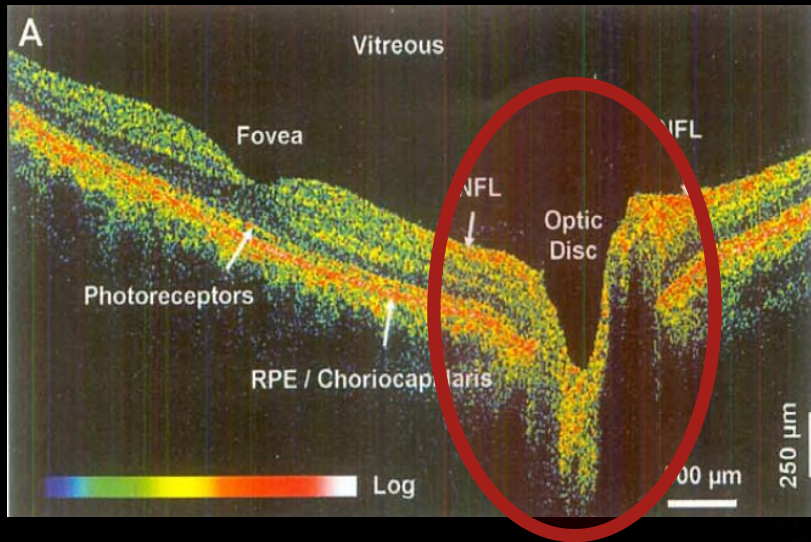
# DIABETIC RETINOPATHY

(IMAGE FROM PREVENT BLINDNESS WEBSITE)



# GLAUCOMA

(IMAGE FROM PREVENT BLINDNESS WEBSITE)



# CATARACTS

(IMAGE FROM PREVENT BLINDNESS WEBSITE)



# THERE ARE OTHER CAUSES OF VISUAL IMPAIRMENT

Clinical Ophthalmology

Dovepress

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ORIGINAL RESEARCH

## Early Lifetime Substance Use and Development of Visual Impairment: Analysis of the National Survey on Drug Use and Health Data

Zain S Hussain<sup>1,2</sup>, Asher Khan<sup>2,3</sup>, Asad Loya<sup>4</sup>, Kaushal Shah<sup>5</sup>, Fasika A Woreta<sup>6</sup>, Kamran M Riaz<sup>2</sup>

<sup>1</sup>University of Medicine and Health Sciences, Basseterre, Saint Kitts and Nevis; <sup>2</sup>Department of Ophthalmology, Dean McGee Eye Institute, Oklahoma City, OK, USA; <sup>3</sup>College of Medicine, University of Oklahoma, Oklahoma City, OK, USA; <sup>4</sup>Department of Ophthalmology, Baylor College of Medicine, Houston, TX, USA; <sup>5</sup>Department of Psychiatry and Behavioral Sciences, Oklahoma State University, Tulsa, OK, USA; <sup>6</sup>Department of Ophthalmology, Johns Hopkins Wilmer Eye Institute, Baltimore, MD, USA

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- A history of abuse of prescription, non-prescription, or illegal substances was significantly associated with self-reported VI.
- All non-prescription substances types (alcohol, cigarettes, inhalants, marijuana) showed similar effects.
- Odds ratios ranged from 1.2 to 2.1.

# SPECIFIC EFFECTS OF VISUAL IMPAIRMENT ARE ALSO ASSOCIATED WITH DISTRESS

- Charles Bonnet Syndrome (visual release hallucinations)
  - Associated with vision loss
  - Psychoeducation can be useful (e.g., in individual counseling; in assisted living, nursing homes, etc.).
- [https://youtu.be/Rerzmm41g\\_Y](https://youtu.be/Rerzmm41g_Y)

# COMMONLY AVAILABLE SERVICES

- Ophthalmology and Optometry
  - Diagnosis, medical treatments
- Vision rehabilitation
  - Low vision therapy
    - Devices, assistive technology, environmental modifications
  - Vision rehabilitation therapy
    - Adaptive living skills in home and other environments
  - Orientation and mobility
    - Indoor and outdoor travel skills using long/white cane, electronic travel devices (e.g., GPS), public transportation use, and use of guide (e.g., dog, human)
- Vocational services

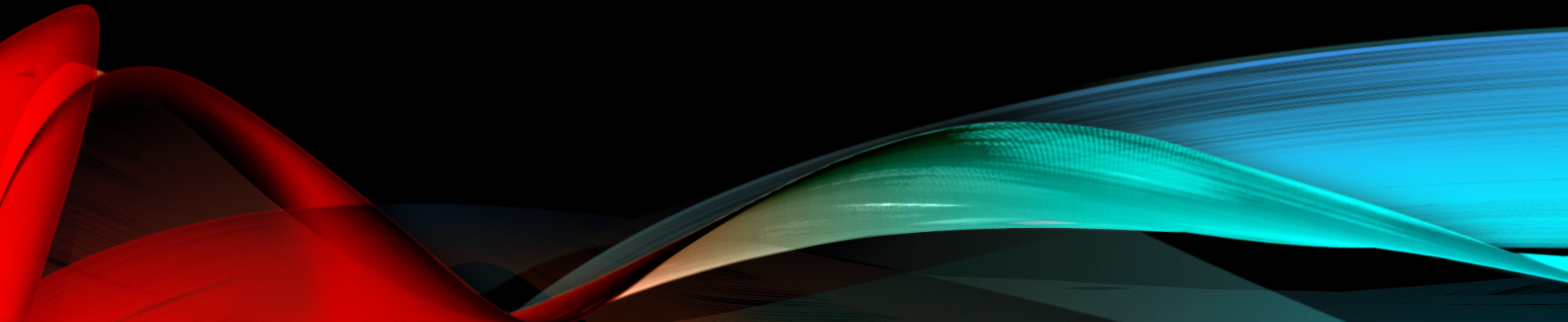


# LIMITS OF REHABILITATION SERVICES ON QUALITY OF LIFE

- Visual impairment can affect every aspect of life (social status, employment, finances, relationships, behavior), including confidence, self-identity and sense of personal value.
- People with B/VI are typically offered rehabilitation and practical solutions regarding orientation and mobility, and job performance.
- Adjusting to blindness, or any other major life change involves 3 components:
  - Knowledge of the facts involved (cognitive)
  - Behaviors involved (action)
  - Feelings involved (affective)

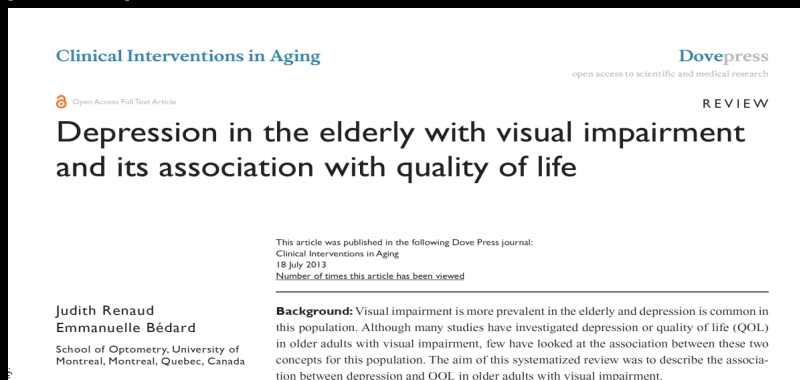
“ADJUSTING WITH BLINDNESS IS LESS THAN SATISFACTORY UNLESS THE INDIVIDUAL REACHES THE POTENTIAL OF SELF-ACCEPTANCE AND SELF-ESTEEM AS A PERSON, FIRST OF ALL, AND THEN AS A PERSON WHO HAPPENS TO BE BLIND.”

(Tuttle & Tuttle, 2004, p. 212)



# DEPRESSION REDUCES QUALITY OF LIFE

- An important factor limiting better outcomes, and perceived quality of life, is untreated depression in people with B/VI.



“Considering the high prevalence rate of depression in this community and its disabling effects on QOL, interventions to prevent and treat depression are essential”

- Depression is the most disabling mental illness, and one of the major sources of disability worldwide.
- In addition, it can act as an obstacle to good VR outcomes.
  - Horowitz, et al., 2005, The effect of rehabilitation on depression among visually disabled older adults. Aging Ment Health;




- When people first access vision rehabilitation services, data from the USA indicate that the prevalence of depression is ~ 30%.

- Brody, et al., 2001, Depression, visual acuity, comorbidity, and disability associated with age-related macular degeneration. *Ophthalmology*;
- Brody, et al., 2005, Self-management of age-related macular degeneration at the 6-month follow-up - A randomized controlled trial. *Arch Ophthalmol*.
- Rovner, et al., 2001, Neuroticism predicts depression and disability in age-related macular degeneration. *J Am Geriatr Soc*.
- Rovner, et al., 1997. Screening for depression in low-vision elderly. *Int J Geriatr Psychiatry*.
- Rovner, et al., 2007. Preventing depression in age-related macular degeneration. *Arch Gen Psychiatry*.

## ORIGINAL ARTICLE

# Association of vision loss and depressive symptomatology in older adults assessed for ocular health in senior living facilities

Steven M Silverstein<sup>1,2,3,4</sup>  | Silvia Sörensen<sup>1,3,5,6</sup> | Anoop Sunkara<sup>7</sup> | Adriann Lai<sup>1</sup> | Samantha I Fradkin<sup>8</sup> | Rajeev S Ramchandran<sup>3,6,9</sup>

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**Correspondence****Abstract**

**Purpose:** People with vision loss are at increased risk for major depressive disorder (MDD) and subclinical depression. However, screening for depression is rarely done in eye care settings or among groups in the general population known to have vision disorders.

**Methods:** We examined the prevalence of depression, using the Patient Health Questionnaire – 2 (PHQ-2), among a group of older adults ( $N = 204$ ; mean age = 82.15) at two senior living facilities (SLFs) and determined the relationships between severity of depression and objective visual findings, visual function, beliefs about taking an active role in one's own eye care (i.e., patient activation) and level of social support.

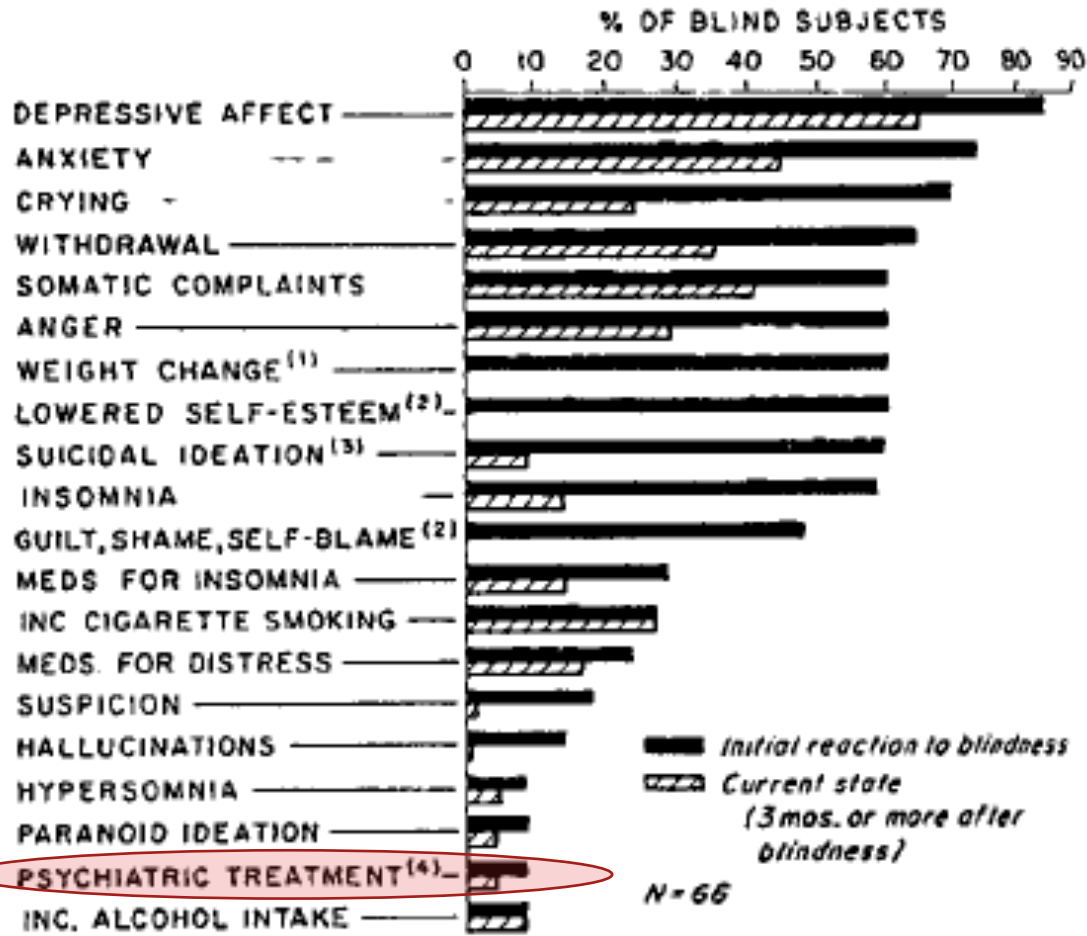
**Results:** Approximately 50% of the sample had impaired vision in at least one eye, and close to 30% of the sample obtained a score on the PHQ-2 indicating the likely presence of major depressive disorder. Visual testing findings were related to visual function (e.g., ability to read), but not to depression. Patient activation was also not significantly related to the level of depression. However, impaired visual functioning and less social support were both strong predictors of depression. These two variables and their interaction accounted for 17% of the total PHQ-2 score variance.

# Reactions to Blindness

An Exploratory Study of Adults With Recent Loss of Sight

Roy G. Fitzgerald, MD, Bethesda, Md

1970, Archives of General Psychiatry



# INTERNATIONAL FINDINGS

COUNTRY	RATE OF DEPRESSION
Thailand	43% (during COVID)
Bangladesh	58% (during COVID)
Brazil	54% (during COVID)
Australia (pts. w/ cataracts)	31%
England (older adults with VI)	30%
Netherlands (older adults with VI)	27%
India (older adults with VI)	21%

Summary from Tantirattanakulchai et al., 2023, Clinical Ophthalmology

# Visual Impairment and Mental Health: Unmet Needs and Treatment Options

This article was published in the following Dove Press journal:  
*Clinical Ophthalmology*

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Steven M Silverstein <sup>2</sup>

<sup>1</sup>Department of Psychology, Rutgers University, Piscataway, NJ, USA;

<sup>2</sup>Departments of Psychiatry, Neuroscience, and Ophthalmology, University of Rochester, Rochester, NY, USA

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**Purpose:** An estimated 2.2 billion people are visually impaired worldwide. Given that age-related vision loss is a primary cause of vision impairment, this number is projected to rise with increases in average lifespan. Vision loss often results in significant disability and is associated with a substantial economic burden, reduced quality-of-life, concurrent medical issues, and mental health problems. In this review, the mental health needs of people with vision impairment are examined.

**Patients and methods:** A review of recent literature on mental health outcomes and current treatments in people with visual impairment was conducted.

**Results:** Considerable data indicate that rates of depression and anxiety are elevated among people with visual impairments. Moreover, individuals of lower socioeconomic status may be at increased risk for vision impairment and subsequent mental health problems. Existing psychosocial interventions for improving mental health in people with visual impairment show some promise, but are limited by low adherence and lack generalizability.

**Conclusion:** In order to improve outcomes, a better understanding of the mechanisms linking visual impairment and poor mental health is needed. It will also be essential to develop more effective interventions and expand access to services to improve the detection and treatment of mental health problems in this population.

**Keywords:** visual impairment, vision loss, mental health, psychosocial interventions

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<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7721280/>



FROM: KESSLER ET AL. 2015, **ANXIOUS** AND  
NON-ANXIOUS MAJOR DEPRESSIVE DISORDER  
IN THE WORLD HEALTH ORGANIZATION  
WORLD MENTAL HEALTH SURVEYS. *EPIDEMIOLOGICAL  
PSYCHIATRY SCI.*


- 45.7% of people with a lifetime history of major depressive disorder had a history of one or more anxiety disorders.
- Anxiety should also be carefully assessed in people with blindness or VI, especially when there is a history of depression.

# ASPECTS OF TREATMENT CAN FURTHER IMPACT MENTAL HEALTH

Clinical Ophthalmology

Dovepress

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ORIGINAL RESEARCH

## Through the Eyes of Patients: Understanding Treatment Burden of Intravitreal Anti-VEGF Injections for nAMD Patients in Norway

Gudrun Reitan<sup>1</sup>, Inga Britt Kjellevoid Haugen<sup>2</sup>, Kristoffer Andersen<sup>3</sup>, Ragnheidur Bragadottir<sup>4,5</sup>, Christian Bindsøll<sup>2</sup>

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Correspondence: Christian Bindsøll, Email christian.bindsoll@roche.com

- 130 nAMD patients responded to the survey. The majority of patients reported to receive nine or more injections per year.
- Many patients needed caregiver support for every treatment appointment (37.7%).
- The week before the treatment, 33.1% of patients reported to be stressed and 15.4% struggled to sleep.
- The majority of patients reported the treatment as uncomfortable (54.6%) or as somewhat painful (26.2%).

# THE PROBLEM IS NOT LIMITED TO ELDERLY PEOPLE

- Among adults over 19 years of age with loss of visual function, the rate of depression is 11.3%, vs. 4.8% of adults without vision loss.
- After controlling for age, sex, race/ethnicity, marital status, living alone or not, education, income, employment status, health insurance, body mass index, smoking, binge drinking, general health status, eyesight worry, and major chronic conditions, **self-reported visual function loss remained significantly associated with depression (overall odds ratio = 1.9)**
  - Zhang et al., 2013, Association between depression and functional vision loss in persons 20 years of age or older in the United States, NHANES 2005-2008. JAMA Ophthalmol.

# COMPONENTS OF DEPRESSION IN

B/VI (FROM DODDS ET AL., 1994, THE CONCEPT OF  
ADJUSTMENT: A STRUCTURAL MODEL, JOURNAL OF VISUAL  
IMPAIRMENT AND BLINDNESS)

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- Depression
- Anxiety
- Low self-esteem
- External locus of control
- Self-defeatist performance beliefs
- Prior negative attitudes towards blind people
- Lack of acceptance of their own sight loss

# CHANGES IN EMOTIONAL REACTIONS FROM TIME OF LOSS OF SIGHT TO UP TO 2 YEARS LATER (N=104) (FROM CONYERS, 1992)

<u>REACTION</u>	<u>IMPROVED</u>	<u>DECLINED</u>
Nothing to get up for	0	17
Nothing to look forward to	3	26
Meaning and purpose left life	2	23
No hope for the future	3	26
Bitter about loss of sight	2	24
Felt sad	3	34
Felt I would not feel again	1	11
Couldn't accept it happened to me	3	35
Could not accept sight would not return	4	26
Felt embarrassed	2	28
Felt so alone in this experience	2	11
Felt like a second class person	2	15

# WHAT MAKES THINGS HARDER

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- Service providers did not ask about mental health issues
- Had to re-construct identity, as a blind person
  - This means different things to different people
  - If pre-blindness attitudes towards blind people were negative, the task is more difficult and depression is often present (Dodds et al., 1991).
  - “The psychologic problems of blindness invariably have at their core the attitude of the patient toward his affliction” (Cholden, 1958).
- Many tasks difficult (e.g., problems when things break)
- Anger (e.g., frustration when people describe things they see)
- Balance can be an issue (e.g., running difficult)
- Stigma
- Harder to be spontaneous in social interactions
- Concerns about attractiveness and sexuality
- Other.....

# INFANTALIZING BEHAVIOR

- “I have always been an active member of my church. Recently, while attending a shower for a member, I went to bite into a cupcake topped with a wonderful fluffy icing. I got the icing on my face. I went to pick up my napkin, and before I could wipe the icing away, someone pushed my head back and proceeded to wipe my face. I didn’t know what to say or do, but I knew I felt humiliated. I don’t want to stop participating, but what do I do with the feelings, and how do I address the situation?” (from “Transition to blindness: A conversation that should happen in the Federation” by Debbie Wunder, Braille Monitor, July 2018, pp. 403-405)



Doretha Smith





Larry Woodard

# STAGES OF PSYCHOLOGICAL ADJUSTMENT TO LOSS OF SIGHT

- From Cholden, 1958, *A Psychiatrist Works With Blindness*
  - Depersonalization
  - Depression
  - Recovery
- From Tuttle & Tuttle, 2004, *Self-Esteem and Adjusting with Blindness\**
  - Trauma, physical or social
  - Shock and denial
  - Mourning and withdrawal
  - Succumbing and depression

---

  - Reassessment and reaffirmation
  - Coping and mobilization
  - Self-acceptance and self-esteem

Reaction

Rebuilding

“THERAPEUTIC INPUT FOR THE VISUALLY IMPAIRED CLIENT GROUP MAY NEED TO TARGET BOTH WELLBEING (FEELINGS ABOUT ONESELF AND THE FUTURE) AND PROBLEMS (DEPRESSION, ANXIETY, PHYSICAL HEALTH, AND TRAUMA)”

*Counselling and Psychotherapy Research*, December 2012; 12(4): 294–302



## **Emotional support and counselling for people with visual impairment: Quantitative findings from a mixed methods pilot study**

WALLY BARR<sup>1\*</sup>, SUZANNE HODGE<sup>2</sup>, MARTINA LEEVEN<sup>3</sup>, LOUISE BOWEN<sup>4</sup>, &  
PAUL KNOX<sup>5</sup>

<sup>1</sup>*Health and Community Care Research Unit, University of Liverpool*, <sup>2</sup>*Division of Health Research, Lancaster University, Lancaster*, <sup>3</sup>*University of Kent, Canterbury*, <sup>4</sup>*Sight Service, Gateshead*, and <sup>5</sup>*Eye and Vision Sciences, University of Liverpool, Liverpool, UK*



## Ableist Microaggressions and the Mental Health of Disabled Adults

Shanna K. Kattari<sup>1</sup>

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### Abstract

Microaggressions perpetuate inequalities and stereotypes against people from marginalized communities. Research demonstrates that ongoing experiences of identity-related microaggressions can negatively impact mental health outcomes, increase somatic symptoms, and increase negative affect. This study explores the relationship between experiences of ableist microaggressions and mental health outcomes among disabled adults by using a quantitative cross-sectional survey of 311 U.S. adults who identify as disabled/having a disability, to examine the correlation between ableist microaggressions (using the AMS-65) and mental health (assessed by the MHI-18). Findings indicate that increased experiences ableist microaggressions are negatively correlated with positive mental health outcomes, and that the visibility of disabilities/impairments are correlated with experiencing ableist microaggressions. These findings can inform the work of counselors, therapists, social workers, and other human service professionals when supporting disabled individuals, recognizing that their mental health may be related to these common and often unintentional oppressive interactions.

**Keywords** Disability · Ableism · Microaggressions · Mental health · Disabled adults

- Increased experiences of ableist microaggressions are negatively correlated with positive mental health outcomes.
- The visibility of the disability is correlated with the frequency of experiencing microaggressions.



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PSYCHOLOGICAL  
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Rehabilitation Psychology

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## Coping With Stigmatization and Discrimination Related to Blindness and Low Vision

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**Purpose/Objective:** Research suggests that effective coping with stress related to stigmatization and discrimination might protect the stigmatized persons against poor mental health outcomes associated with experiencing stress. Despite this, research specifically on coping with social stigma among people who are blind or have low vision has received less attention. We addressed this gap in the literature, by exploring the lived experiences of people who are blind or have low vision with regard to their perceptions of stigma and their coping responses. **Research Method/Design:** We employed a qualitative research method using an Interpretative Phenomenological Analysis (IPA). Participants were 11 Australians who were blind or had low vision, aged between 18 to 65 years, and were recruited via advertisement. Data was collected using in-depth interviews and was subjected to data analysis using IPA. **Results:** Two sets of themes emerged from the data analysis which we classified under 2 superordinate themes labeled as Ways of Coping and Coping Skills and Resources. **Conclusions/Implications:** This study highlights the significance of personal and contextual aspects of coping with stigma and discrimination by demonstrating the complex nature of how people who are blind or have low vision cope with stigma. Coping efforts might be tenuous and require cognitive and/or behavioral skills and psychological resources and as such, individuals experiencing stigma might benefit from interventions aimed at improving coping skills and resources, such as self-advocacy, assertion, or positive reinterpretation.

- People with blindness or low vision frequently encounter stigmatization in their daily lives (Frederick, 2015; Hess, 2010; Jessup et al., 2013).
- This can lead to:
  - not participating in rehabilitation programs (Southall & Wittich, 2012)
  - limited social inclusion (Bennion et al., 2012; Kong & Loi, 2017)
  - a reduced sense of mastery
  - anger
  - feeling uncomfortable in varied social interactions
  - shame and embarrassment (J. Green et al., 2002; Nyman et al., 2012; Thombs & de Board, 2016).
- Despite this, coping with stigma in this population is an understudied area.

# CONCERN ABOUT STIGMATIZATION CAN EXIST EVEN IN SAFE SPACES

- From “Transition to blindness: A conversation that should happen in the Federation” by Debbie Wunder, Braille Monitor, July 2018, pp. 403-405:
  - “My predominant reaction to vision loss has been surprise: surprise at how much I used my vision, surprise at the grief I had in losing it, and surprise at how reluctant I have been to talk about it in the NFB, where everyone seems to have adjusted to it without the pain or the difficulty I have experienced.”
  - “It is just as safe to talk about our struggles as it is our successes and...we are not lesser Federationists because sometimes we hurt about things we have lost.”

# BENEFITS OF ROLE MODELS

“Very soon after I went blind, I went to my first convention of the National Federation of the Blind. Though as a six-year old I was not scared about my future as a blind person, learning about the NFB and going to conventions showed me tons of independent blind people who I could look up to. Real life superheroes that I could aspire to be like.” – Abigail (in *Braille Monitor*, May 2023)

# THE OTHER PROBLEM

- **Insufficient counseling and emotional support is available to people with visual impairments.**
  - Conyers, 1992, *Vision For The Future*.
- “The literature is silent regarding proper approaches to diagnosing and managing suicidality among patients with visual impairment, especially age-related macular degeneration”
  - Johnson et al., 2014, *Suicide and Visual Loss: A Case Report Reflecting the Need for Recognition and Management in Ophthalmological Settings*. *Semin Ophthalmol*





Natalie Watkins

# OVER 1/3 OF PEOPLE BELIEVE THEY NEED EMOTIONAL HELP AND COUNSELING AT THE TIME THEY BEGIN RECEIVING SERVICES FOR B/VI

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- “If I had someone to talk with about my loss of sight; I would have appreciated psychological help to discuss emotional problems, such as anger and grief. Right now I would still like and appreciate this help” (Conyers, 1992)
- ~25% of people said they felt unable to talk to people in their life about their concerns (Conyers, 1992)

# PRIMARY BARRIERS TO ADDRESSING MH NEEDS

(FROM PREVENT BLINDNESS: VISION LOSS AND MENTAL HEALTH: KEY TAKEAWAYS FROM AN INTERPROFESSIONAL TASK FORCE)

- Limited awareness of MH needs among eye care providers
- Limited time to address MH needs in eye clinic appts.
- Shortage of trained providers with knowledge and experience regarding vision loss and coping with it
- Stigma (self-stigma, from potential providers)
- Resistance to referring patients to non-ophthalmic services (i.e., vision rehabilitation, mental health counseling) due to belief that this represents 'giving up'

# ANOTHER PROBLEM

- Literature reviews indicate that current services are not very effective.....



REVIEW PAPER

## **Psychosocial interventions to improve mental health in adults with vision impairment: systematic review and meta-analysis**

Hilde P. A. van der Aa<sup>1</sup>, Tom H. Margrain<sup>2</sup>, Ger H. M. B. van Rens<sup>1,3</sup>, Martijn W. Heymans<sup>4</sup> and Ruth M. A. van Nispen<sup>1</sup>

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**Citation information:** van der Aa HPA, Margrain TH, van Rens GHMB, Heymans MW & van Nispen RMA. Psychosocial interventions to improve mental health in adults with vision impairment: systematic review and meta-analysis. *Ophthalmic Physiol Opt* 2016; 36: 584–606. doi: 10.1111/opo.12313

STUDY PROTOCOL

Open Access

# The Depression in Visual Impairment Trial (DEPVIT): trial design and protocol

Tom H Margrain<sup>1\*</sup>, Claire Nollett<sup>1</sup>, Julia Shearn<sup>1</sup>, Miles Stanford<sup>3</sup>, Rhiannon Tudor Edwards<sup>4</sup>, Barbara Ryan<sup>1</sup>, Catey Bunce<sup>5</sup>, Robin Casten<sup>6</sup>, Mark T Hegel<sup>7</sup> and Daniel J Smith<sup>2</sup>

Low Vision

## Depression in Visual Impairment Trial (DEPVIT): A Randomized Clinical Trial of Depression Treatments in People With Low Vision

IOVS, 2016

Claire L. Nollett,<sup>1</sup> Nathan Bray,<sup>2</sup> Catey Bunce,<sup>3</sup> Robin J. Casten,<sup>4</sup> Rhiannon T. Edwards,<sup>2</sup> Mark T. Hegel,<sup>5</sup> Sarah Janikoun,<sup>6</sup> Sandra E. Jumbe,<sup>7</sup> Barbara Ryan,<sup>1</sup> Julia Shearn,<sup>8</sup> Daniel J. Smith,<sup>9</sup> Miles Stanford,<sup>6</sup> Wen Xing,<sup>3</sup> and Tom H. Margrain<sup>1</sup>

Results of this trial of Problem Solving Therapy (PST) were not significant. More than 6-8 sessions focusing on solving practical problems is needed to adequately address mental health issues!

# THE IMPORTANCE OF SOCIAL SUPPORT

Clinical Ophthalmology

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ORIGINAL RESEARCH

## Impact of COVID-19 on Depressive Symptoms Among Patients with Low Vision and Blindness

Pankaew Tantirattanakulchai<sup>1</sup>, Nuchanad Hounnakklang<sup>1</sup>, Pear Ferreira Pongsachareonnont<sup>2,3</sup>, Bharkbhum Khambhiphant<sup>4</sup>, Suwanchai Hounnakklang<sup>5</sup>, Nanda Win<sup>1</sup>, Suchon Tepjan<sup>6</sup>

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- Greater perceived social support was significantly associated with lower levels of depression.
- More negative social support (e.g., perceived overprotection) and less positive social support were related to more depression (Papadopoulos et al., 2014, *Res Dev Disabil.*)
- Negative social support associated with more functional disability and reduced sense of mastery over everyday tasks (Cimarolli et al., 2006, *J. Gerontology*).

# RECOMMENDATIONS

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- People with vision loss and significant mental health issues should have available to them support, counseling or therapy with counselors specifically trained to work with people who are recovering (internally and externally) from losing their sight.
- Counseling should be an available precursor to rehabilitation, thereby potentially increasing the likelihood of effective practical intervention (Conyers, 1992).
- Services for *many* people with B/LV would be “enriched by concern with meeting ‘internal’ needs and concerns, with the emphasis shifting away from mainly quantifiable, ‘external’ and visible provision and activity (Conyers, 1992).
- People with lived experience of vision loss may be especially useful in providing these services.

# KEY ISSUES FOR MH PROVIDERS

(FROM PREVENT BLINDNESS: VISION LOSS AND MENTAL HEALTH: KEY TAKEAWAYS FROM AN INTERPROFESSIONAL TASK FORCE DOCUMENT)

- **Change or loss of identity:** Individuals who develop vision loss in adulthood might not be able to do the things they once did, or not in the same way, and that involves loss and often a shift in identity.
- **Loss of independence:** Acute depression and anxiety among those with vision loss is often a reflection of losing independence and adjusting to new life circumstances. It is important to consider resources that might help patients safely re-gain their independence and self-efficacy.
- **Emotions, Tracking, and Recall:** A flood of emotions (such as shock, fear, devastation, anxiety, anger) may interfere with remembering medical information. Provide extra time for emotional and cognitive processing.
- **Grief and coping:** Anticipatory grief or anxiety related to gradual vision loss is different than a possible life-threatening situation sometimes associated with sudden traumatic vision loss, and different still from grief that sometimes accompanies inherited or congenital eye conditions. No matter their circumstances, patients can benefit from being asked about how they are coping and what supports they have in place.



## Questions to ask that communicate empathy

**I imagine it is hard adjusting to your vision loss. How are you holding up?**

This normalizes the grief and loss process and shows you care.

**Would you like to talk to someone about how you are feeling?**

Phrasing the question in such a way can get around the mental health stigma that many people have internalized.

**Tell me about how you have previously coped with difficult situations?**

Reminding them of the skills they already have to manage challenging situations and emotions is a crucial component to providing support.

Figure from Prevent Blindness: Vision Loss and Mental Health: Key Takeaways from an Interprofessional Task Force document



## Training for eye care, primary care, and mental health providers

- Increase training for eye care providers on the importance of empathetic communication and asking their patients about their mental health, how they are coping, and what their support network looks like.
- Increase training for eye care providers and primary care providers on the grief process unique to this population and applicable resources to support mental wellness.
- Increase training for mental health providers about the “patient journey” of living with or anticipating vision loss or blindness and how they can assist them throughout their psychosocial and relational transitions.

Figure from Prevent Blindness: Vision Loss and Mental Health: Key Takeaways from an Interprofessional Task Force document



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### Integrated eye care model

- Considered the gold standard.
- Develop an integrated eye health care model that includes patient navigators, peer support teams, mental health professionals (social workers, psychologists, and psychiatrists) and other care professionals to provide and connect patients to services they need.

Recommendations and figure from Prevent Blindness: Vision Loss and Mental Health: Key Takeaways from an Interprofessional Task Force document

# RESOURCES FOR BEHAVIORAL HEALTH PROVIDERS

- **The Hadley School**, online courses, especially Blindness Basics:  
<https://hadley.edu>
- **Living Blind** (formerly Life in BALANCE) **podcast**:  
<https://podcasts.apple.com/us/podcast/living-blind/id1557180709>
- **Blind Guy Travels** **podcast**:  
<https://www.radiotopia.fm/podcasts/blind-guy-travels>
- **RNIB (Royal National Institute for the Blind)** **podcasts**:  
<https://podcasts.apple.com/gb/podcast/rnib-conversations/id1361038809>
- **VI Talk** **podcast**: <https://podcasts.apple.com/us/podcast/vi-talk/id846252096>
- **Prevent Blindness**: <https://preventblindness.org>
- Many useful first person books, and books by mental health experts (e.g., Crashing Through by Robert Kurson; A Psychololgist Looks at Blindness by Alan Dodds)

# MORE RESOURCES

## (LIST FROM PREVENT BLINDNESS)

- **Living Well With Low Vision:** [LowVision.PreventBlindness.org](http://LowVision.PreventBlindness.org)
- **ASPECT Patient Engagement Program:** [CVPH.PreventBlindness.org/Aspect-Program](http://CVPH.PreventBlindness.org/Aspect-Program)
- **VisionServe Alliance:** [VisionServeAlliance.org](http://VisionServeAlliance.org)
- **Vision Aware:** [VisionAware.org](http://VisionAware.org)
- **National Suicide Prevention Lifeline (988):** [988Lifeline.org/Talk-to-Someone-Now](http://988Lifeline.org/Talk-to-Someone-Now)
- **OIB-TAC at Mississippi State University:** [OIB-TAC.org](http://OIB-TAC.org)
- **American Printing House for the Blind:** [APH.org](http://APH.org)
- **American Foundation for the Blind:** [AFB.org](http://AFB.org)
- **American Council of the Blind:** [ACB.org](http://ACB.org)
- **National Federation of the Blind:** [NFB.org](http://NFB.org)
- **National Council of State Agencies for the Blind:** [NCSAB.org](http://NCSAB.org)

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Journal of the American Society of Ophthalmic Registered Nurses

INSIGHT

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Steven M. Silverstein, PhD; Alicia Lukachko, DrPH, MSW, LSW

PROFESSIONAL DIRECTIONS

## Challenges and Milestones in Implementing a Peer-Support Helpline to Assist People Who Are Emotionally Adjusting to Blindness or Low Vision

CONVERGING DATA from multiple countries indicate that a large proportion of people who lose all or a substantial portion of their vision experience significant depression over the short term. For many in this population, depression can persist even after learning new skills to handle everyday tasks. Studies also indicate that some interventions

can enhance emotional and functional well-being and has obvious benefits. Enabling the development of additional similar programs throughout the United States could improve the lives of millions of people, but achieving this goal requires overcoming several technical and psychological biases.

### Review of the Literature: Rationale for Developing the Program

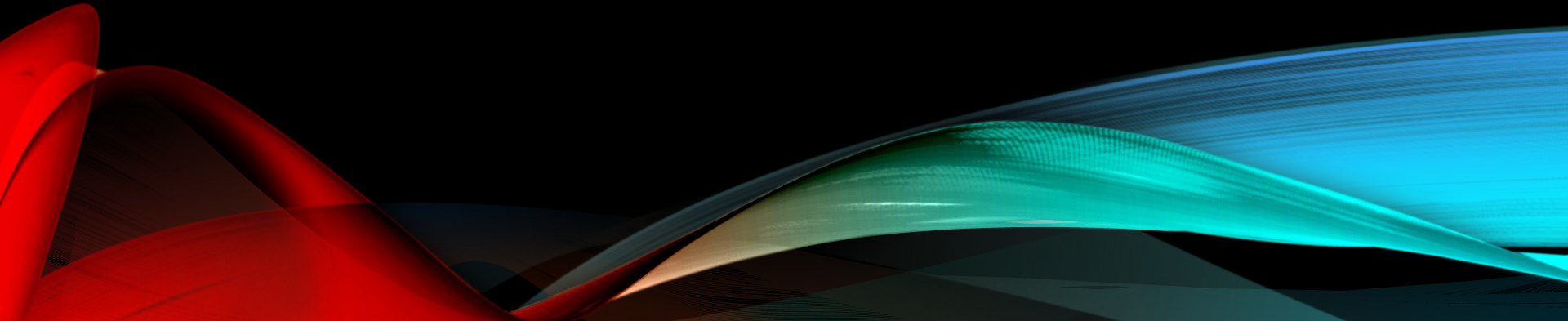
Visual impairment can affect every aspect of life (social status, employment, finances, relationships, behavior) including confidence, self-identity, and sense of personal value. Traditional services for people who are blind

# SUMMARY

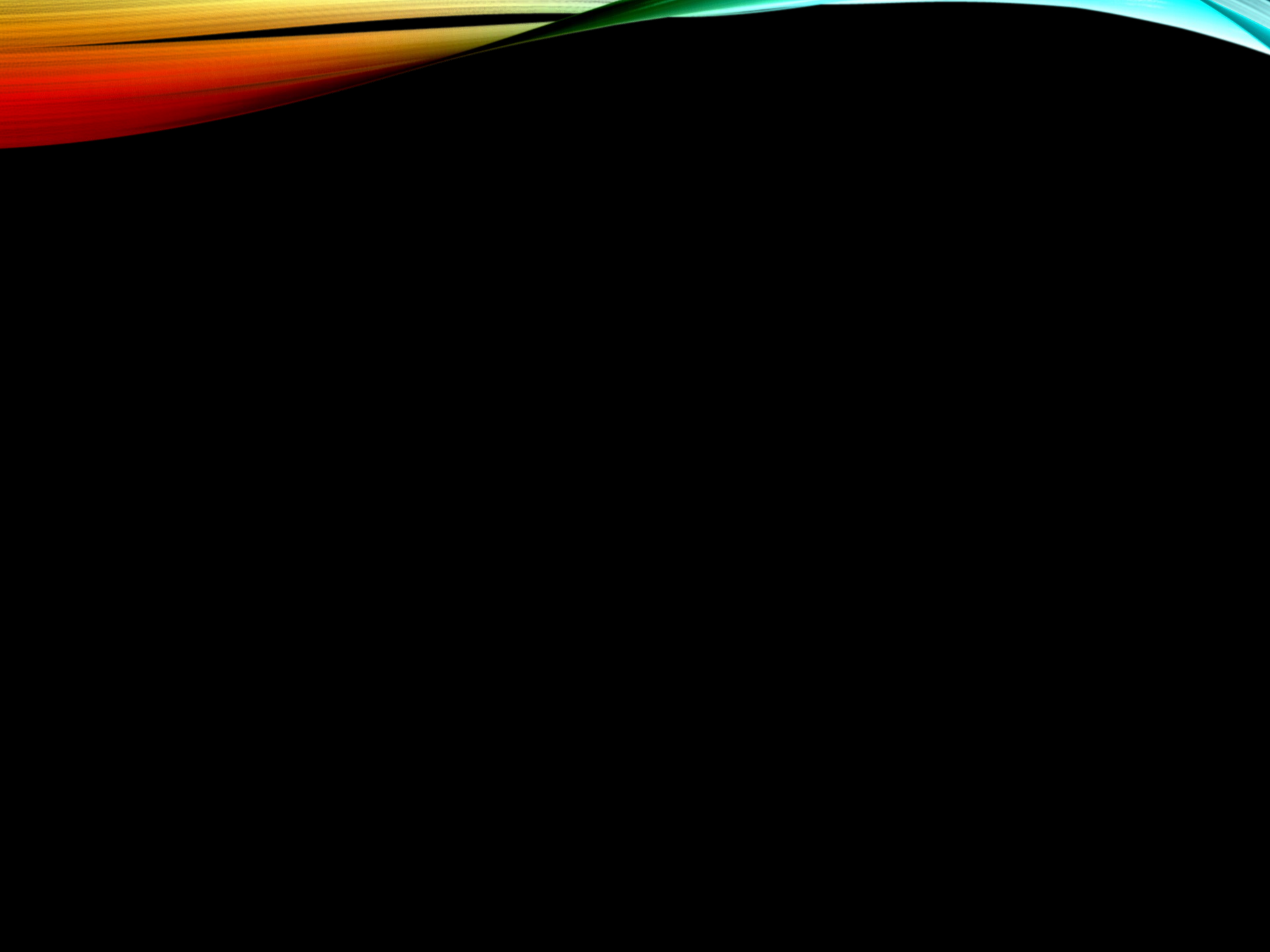
- Conditions that affect vision can have short-term and long-term effects on mental health.
- A significant proportion of people with blindness or vision loss express a desire for assistance with mental health needs.
- Such services are generally not available.
- Rehabilitative services are useful but cannot be counted on to improve emotional well-being
- Problem-solving therapies have not shown an ability to reduce depression.
- Peer support services are available but evidence on their effectiveness is lacking.
- Clinicians experienced and/or trained in working with people going through the stages of adjusting to living with blindness are needed.
- Integrated eye and mental health care is realistic and needed.

THANK YOU!

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# CONTRAST SENSITIVITY

## BRIEF REPORTS

### Seeing Gray When Feeling Blue? Depression Can Be Measured in the Eye of the Diseased

Emanuel Bubl, Elena Kern, Dieter Ebert, Michael Bach, and Ludger Tebartz van Elst

**Background:** Everyday language relates depressed mood to visual phenomena. Previous studies point to a reduced sensitivity of subjective contrast perception in depressed patients. One way to assess visual contrast perception in an objective way at the level of the retina is to measure the pattern electroretinogram (PERG). To find an objective correlate of reduced contrast perception, we measured the PERG in healthy control subjects and unmedicated and medicated patients with depression.

**Methods:** Forty patients with a diagnosis of major depression (20 with and 20 without medication) and 40 matched healthy subjects were studied. Visual PERGs were recorded from both eyes.

**Results:** Unmedicated and medicated depressed patients displayed dramatically lower retinal contrast gain. We found a strong and significant correlation between contrast gain and severity of depression. This marker distinguishes most patients on a single-case basis from control subjects. A receiver operating characteristic analysis revealed a specificity of 92.5% and a sensitivity of 77.5% for classifying the participants correctly.

**Conclusions:** Because PERG recording does not depend on subjective ratings, this marker may be an objective correlate of depression in human beings. If replicated, PERG may be helpful in further animal and human research in depression.

BJPsych

The British Journal of Psychiatry (2012)  
201, 151–158. doi: 10.1192/bjp.bp.111.100560

### Effect of antidepressive therapy on retinal contrast processing in depressive disorder

Emanuel Bubl, Dieter Ebert, Elena Kern, Ludger Tebartz van Elst\* and Michael Bach\*

#### Background

Recently, we reported a reduced retinal contrast gain in unmedicated and medicated patients with major depression.

#### Aims

To analyse whether the contrast gain normalises after successful antidepressive therapy by recording the pattern electroretinogram (PERG) in healthy controls and patients with depression before and after antidepressive therapy.

#### Method

Fourteen patients diagnosed with major depression were repeatedly scanned and the results compared with that from 40 matched controls.

#### Results

The retinal contrast gain was lower at baseline in patients

with depression, was normalised with remission and correlated with the severity of depression. Patients who did not achieve remission retained significantly lower contrast gain at follow-up.

#### Conclusions

The study provides evidence for a state-dependent modulation of retinal contrast gain in patients with major depression. Reduced contrast gain normalised after therapy. A PERG-based contrast gain could serve as a state marker of depression.

#### Declaration of interest

None.

# Question and Answer



# Evaluation Information

The MHTTC Network is funded through SAMHSA to provide this training. As part of receiving this funding we are required to submit data related to the quality of this event.

At the end of today's training please take a moment to complete a **brief** survey about today's training.





Northeast and Caribbean (HHS Region 2)

**MHTTC**

Mental Health Technology Transfer Center Network  
Funded by Substance Abuse and Mental Health Services Administration

## **Assessing Experiences, Knowledge, Attitudes and Needs of Mental Health Providers in Delivering Services and Supports to Individuals who are Blind or Visually Impaired**

*The Northeast & Caribbean Mental Health Technology Transfer Center (MHTTC) is currently conducting a research study to increase our collective understanding of the experience, knowledge, attitudes, and perceived needs of mental health providers in delivering services and supports to individuals who are blind or visually impaired. With the information gained from this survey, we hope to better support clinicians and increase access to quality care.*

*Participation in the study involves completion of a short 15 to 20 minute survey and qualifies you for a chance (via raffle) to win a \$25.00 Amazon gift card. To access the online survey, please use the link below.*

**Access the Survey: [bit.ly/3MSQaPt](https://bit.ly/3MSQaPt)  
Or scan the QR Code**





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