# The Patient Beyond the Pathology

**UMSL OPTOMETRY ACADEME 2026**

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## FINANCIAL DISCLOSURES

- None

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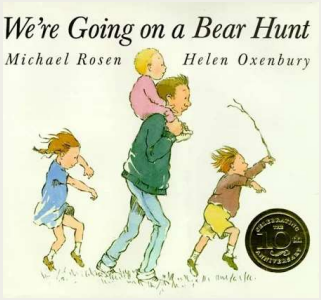


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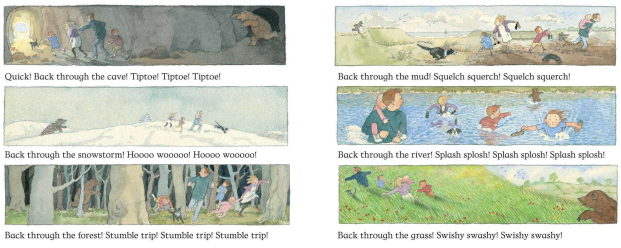


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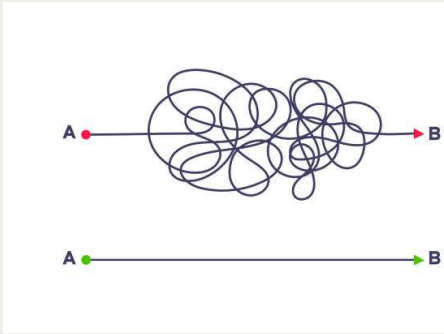


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## OVERVIEW

| Intro | Case I | Case II | Case III | Conclusion |
|---|---|---|---|---|
| Narrative medicine and the parallel chart | *I don't want to do this* | *I can't do this* | *I'm not going to do this* | Takeaways |

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## OBJECTIVES

- Understand basic concepts of narrative medicine
- Recognize signs of passive suicidal ideation and conduct suicide screening using an evidence-based tool
- Assess medication adherence and identify barriers to effective medication management
- Demonstrate active listening when exploring patient concerns and reluctance to pursue treatment
- Apply a whole-person approach to patient care that extends beyond disease pathology

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# Intro

## BASICS OF NARRATIVE MEDICINE

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## NARRATIVE MEDICINE

- Medicine practiced with narrative competence
- Narrative competence: ability to acknowledge, absorb, interpret and act on the stories and plights of others
- We don't just fix problems; we help patients navigate health-illness continuum

Charon, R. JAMA. 2021.

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## THE PARALLEL CHART

- One side what typically makes it into the standard medical record
- The other side, the more complexities of care, non-medical narrative account of a patient encounter
  - Patients' life, experiences, fears, hopes, social context
- Writing about the patient as a person rather than a case
- Like paths of caring for patients

Glasberg, E. Columbia News. 2023.

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## THE PARALLEL CHART EXAMPLE

67yo M with +DM type II presents for 6mo glaucoma suspect follow up:
- ONH suggestive OU
- Last VF nonglc defects
- Tmax 23/23

Somber during introduction, using few words to answer questions, not his usual self

Ask about doing VF during dilation, reports not up for it today, seems in rush to leave

Admits he lost his son last week

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# Case I

***I don't want to do this.***

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## CASE I

74yo M with +HTN presents for 6mo follow up of macular degeneration OU:

- BCVA 20/70, 20/200
- OD RPE atrophy/dry changes, OS disciform scar from previous net S/P anti-vegf injections x yrs
- Recently seen in low vision clinic

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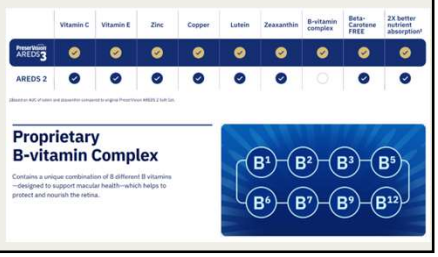
## CASE I

Newer treatments for dry macular degeneration:

- AREDS3
- Photobiomodulation




Preservision

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## CASE I

Newer treatments for dry macular degeneration:

- AREDS3
- Photobiomodulation

**LIGHTSITE III**

**13-Month Efficacy and Safety Evaluation of Multiwavelength Photobiomodulation in Nonexudative (Dry) Age-Related Macular Degeneration Using the Lumithera Valeda Light Delivery System**

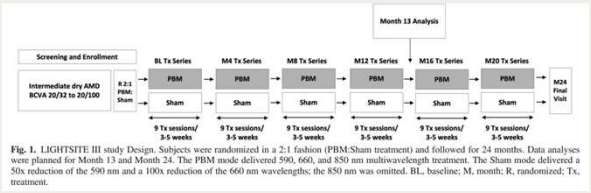


Fig. 1. LIGHTSITE III study Design. Subjects were randomized in a 2:1 fashion (PBM:Sham treatment) and followed for 24 months. Data analyses were planned for Month 13 and Month 24. The PBM mode delivered 590, 660, and 850 nm multiwavelength treatment. The Sham mode delivered a 50x reduction of the 590 nm and a 100x reduction of the 660 nm wavelengths; the 850 nm was omitted. BL, baseline; M, month; R, randomized; Tx, treatment.

Boyer, D. et al. Retina. 2024.

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## CASE I

Newer treatments for dry macular degeneration:

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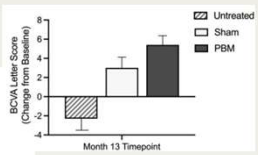


**5.4 – 3 letters = 2.4 letters**

Boyer, D. et al. Retina. 2024.

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## CASE I

Newer treatments for dry macular degeneration:

- AREDS3
- Photobiomodulation

Table 1. Demographics and Baseline Characteristics

| Variable | PBM (N = 65) n (%) | Sham (N = 35) n (%) |
|---|---|---|
| Age (years) | | |
| Mean (SD) | 74.4 (7.3) | 77.1 (6.2) |
| Minimum-maximum | 53–91 | 66–88 |

Boyer, D. et al. Retina. 2024.

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## CASE I

Newer treatments for dry macular degeneration:

- AREDS3
- Photobiomodulation

Table 3. Ocular AEs by System Organ Class and Preferred Term in Study Eyes

| Preferred Term | Study Eyes PBM (N = 93) n (%) | Sham (N = 55) n (%) | Total (N = 148) n (%) |
|---|---|---|---|
| Eye disorders | 21 (22.6) | 12 (21.8) | 33 (22.3) |
| Neovascular age-related macular degeneration | 5 (5.4) | 1 (1.8) | 6 (4.1) |

Boyer, D. et al. Retina. 2024.

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## CASE I: THE PARALLEL CHART

74yo M with +HTN presents for 6mo follow up of dry macular degeneration OU:
- BCVA 20/70, 20/200
- OD RPE atrophy/changes, OS disciform scar from previous net S/P anti-vegf inj
- Recently seen in low vision clinic

Patient casually mentions during case history

***If this is how my vision is going to be, I don't want to continue living like this.***

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## CASE I

Suicidal ideation- why?
- Decreased independence, social skills, income, QOL
- Increased mental health concerns, isolation
- Hopelessness

Kim CY, et al. JAMA. 2024.

20

## CASE I

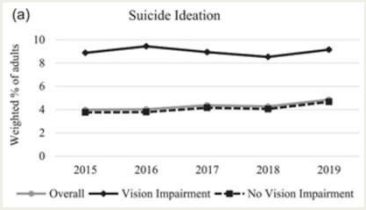
Suicidal ideation and vision loss
- National survey of adults asked if they had any suicidal thoughts, plan, attempts within the last 12mos

Lee OE, et al. J Clin Psychol. 2022.

21

## CASE I

National survey of adults asked about suicidal thoughts, plans, actions




Lee OE, et al. J Clin Psychol. 2022.

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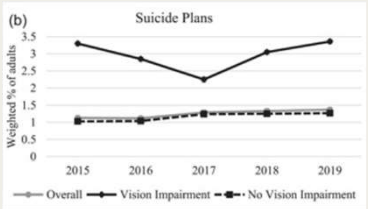
## CASE I

National survey of adults asked about suicidal thoughts, plans, actions




Lee OE, et al. J Clin Psychol. 2022.

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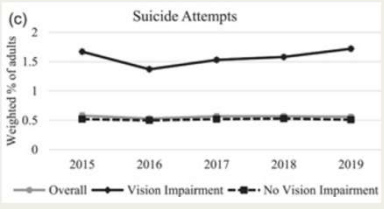
## CASE I

National survey of adults asked about suicidal thoughts, plans, actions




Lee OE, et al. J Clin Psychol. 2022.

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## ASSESSMENT FOR SUICIDE

Suicidal ideation and vision loss

- Columbia Suicide Severity Rating Scale (CSSR)
  - Comprehensive measure of the most essential, evidence-based items needed for thorough risk assessment
- Color-coded with clear definition of level of risk and guidance for next steps


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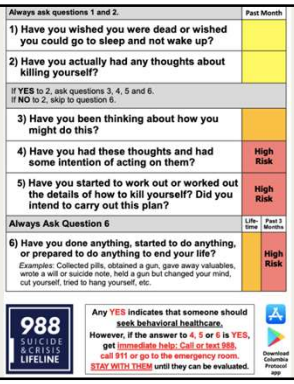


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## ASSESSMENT FOR SUICIDE

Tips

- State why you are asking
- Ask questions in conversational, warm manner
- Be direct, matter-of-fact
- Respond with balance of calm and concern
- Talking about suicide does not increase risk of suicidal behavior
- Assessing suicide risk is protective


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## CASE I: THE PARALLEL CHART

Patient casually mentions during case history

***If this is how my vision is going to be, I don't want to continue living like this.***

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# Case II

***I can't do this.***

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## CASE II

49yo M with +HTN presents for 4mo follow up for moderate POAG:

- BCVA 20/20, 20/20
- IOP today 25/26 (Tmax 29/30) on latan
- ONH moderate OS>OD
- OCT and HVF as follows

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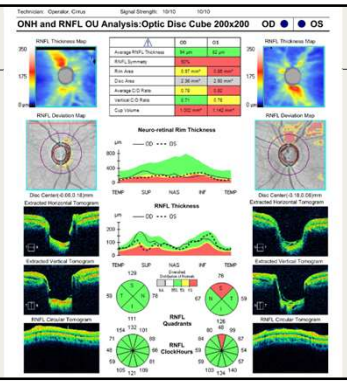
## CASE II

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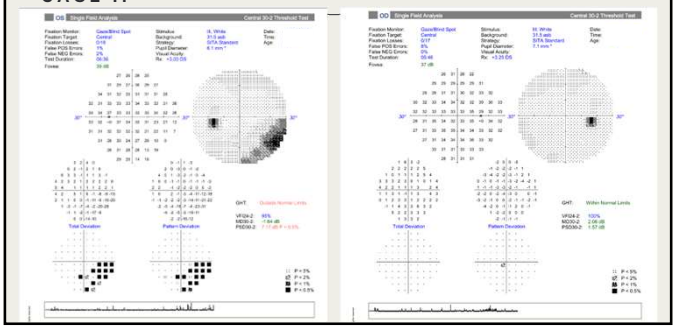
## CASE II



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## Glaucoma Treatment Options

- Add/change drops
- SLT
- Surgical procedures

How do we decide?

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## CASE II: THE PARALLEL CHART

49yo M with +HTN presents for 4mo follow up for moderate POAG:
- BCVA 20/20, 20/20
- IOP today 25/26 (Tmax 29/30) on latan
- ONH and visual fields with moderate glc defects

When asked about medication use, patient states:

***Doc, I haven't been using my eye drops much.***

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## THE NONCOMPLIANT PATIENT

1. Do not understand the nature of their illness
2. Misunderstand or cannot follow physician's advice
3. Do not trust their physician
4. Priorities differ from those their physician has for them
5. Cannot manage their own lives
6. Believe the physician is responsible for their health

Spaeth, G. Ophthalmic Surgery. 1995.

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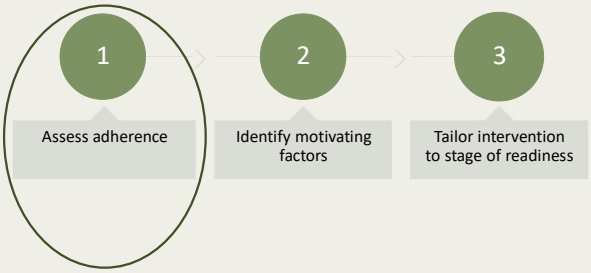
## THE NONCOMPLIANT PATIENT




Hahn SR. American Academy of Ophthalmology. 2009.

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## THE NONCOMPLIANT PATIENT

- Motivational interviewing
  - "An evidence-based collaborative conversational style for strengthening a person's own motivation and commitment to change."
  - Change comes from within
  - Working *with*, rather than *at*

Blankenship, BB. Student Success Journal. 2024.

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## ASSESS ADHERENCE

1. Open-ended question about medication use
2. Explicitly acknowledge taking medication is difficult and normalize missing
3. Ensure understanding regarding honesty and treatment decisions
4. Ask directly about adherence*

Hahn SR. American Academy of Ophthalmology. 2009.

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## ASSESS ADHERENCE

An antidote to judgment is curiosity.

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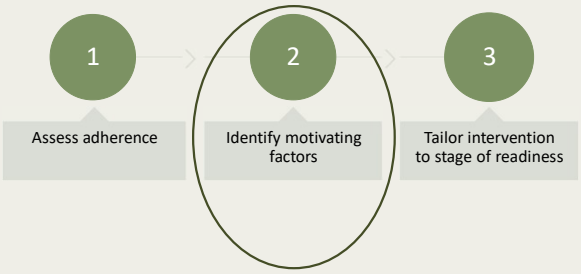
## THE NONCOMPLIANT PATIENT




Hahn SR. American Academy of Ophthalmology. 2009.

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## IDENTIFY MOTIVATING FACTORS

Ask – Patient's current understanding and concerns about the disease and medications

Tell – Respond to what is correctly known and clarify misunderstandings

Ask – See how much was understood and assess any change in motivation

Hahn SR. American Academy of Ophthalmology. 2009.

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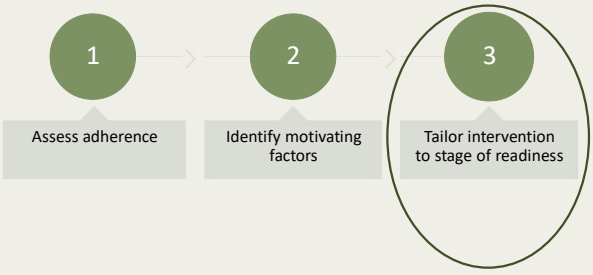
## THE NONCOMPLIANT PATIENT




Hahn SR. American Academy of Ophthalmology. 2009.

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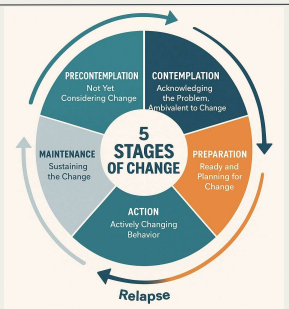
## STAGE OF READINESS FOR CHANGE MODEL




Big Sky Treatment

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## THE NONCOMPLIANT PATIENT

JAMA Ophthalmology | Original Investigation

**Effect of the Support, Educate, Empower Personalized Glaucoma Coaching Program on Medication Adherence**
The SEE Program Randomized Clinical Trial

Paula Anne Newman-Casey, MD, MS; Leslie M. Niziol, MS; Ming-Chen Lu, MS; Deborah Darnley-Fisch, MD; Nauman Imami, MD; Jamie Mitchell, PhD; Chamisa MacKenzie, MSW, MPH; Michele Heisler, MD, MPA

Randomized Controlled Trial > J Surg Educ. 2026 May;83(5):103913.
doi: 10.1016/j.jsurg.2026.103913. Epub 2026 Mar 13.

**Applying Motivational Interviewing to Improve Counseling on Glaucoma Management and Medication Adherence: A Pilot Study With Ophthalmology Residents**

Nisha Chadha [1], Jenny J Lin [2]

JAMA Ophthalmology. Journal of Surgical Edu. 2026

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## THE NONCOMPLIANT PATIENT

1. Assess adherence
2. Identify motivating factors
3. Tailor intervention to stage of readiness

Hahn SR. American Academy of Ophthalmology. 2009.

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## CASE II: THE PARALLEL CHART

When asked about medication use, patient states:

***Doc, I haven't been using my eye drops much.***

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# Case III

***I'm not going to do this.***

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## CASE III

68yo M with +DM type II presents for follow up of moderate NPDR with DME OU:

- LTFU for 1.5 years
- Seen by retina
- BCVA 20/40, 20/40
- DME that meets tx criteria
- A1C 7.2%, DM for ~20 years

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## DME Treatment Options

- Anti-VEGF agents
- Ozurdex implant
- Focal/grid laser photocoagulation

What do we do?

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## CASE III: THE PARALLEL CHART

68yo M with +DM type II presents for follow up of moderate NPDR with DME OU:
- LTFU for 1.5 years
- Seen by retina
- BCVA 20/40, 20/40
- DME that meets tx criteria

When discussing treatment options, patient gets angry and states:

***No one is putting a needle or laser in my eyes. I'm not doing it- I'd rather go blind.***

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## C.A.R.E.S. FOR ANGRY PATIENTS

**C = C**heck yourself
**A = A**ctive listening
**R = R**estate concerns
**E** = **E**mpathize and validate
**S** = **S**olution by the patient

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## C = CHECK YOURSELF

"Check yourself before you wreck yourself."
– Ice Cube

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## A = ACTIVE LISTENING

- Start with open-ended question
- "Magic minute"
- You have the right to respectful communication

Lazoritz, S. The Physician Executive. 2004.

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## R = RESTATE CONCERNS

- Repeat back to them their concerns
- Useful to rephrase as unmet expectation

Lazoritz, S. The Physician Executive. 2004.

54

## E = EMPATHIZE AND VALIDATE

- Complaints are always tied to an emotion or feeling
- Giving space to express feelings is therapeutic
- Offer empathetic statements

Lazoritz, S. The Physician Executive. 2004.

55

## S = SOLUTION BY PATIENT

- Ask patient to offer solution
- We may assume what they want, but ask directly
- Shifts focus back on the present
  - Note: no defense

Lazoritz, S. The Physician Executive. 2004.

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## C.A.R.E.S. FOR ANGRY PATIENTS

**C = C**heck yourself
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## CASE III: THE PARALLEL CHART

When discussing treatment options, patient gets angry and states:

***No one is putting a needle or laser in my eyes. I'm not doing it- I'd rather go blind.***

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## CASE III: THE PARALLEL CHART

Natural history of DME per ETDRS focal laser study

- Visual acuity results at 3 years:
  - 12% tx lost 3 or more lines
  - 24% untx lost 3 or more lines

Limitations to our treatments

- RISE/RIDE NNT ~3

ETDRS Report I. 1985.

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## CASE III

- Wanted to be able to read

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## CONCLUSION

- Path to caring for patients is not always linear
- Healing does not always equal curing
- Narrative medicine can provide tools for us to deeply hear our patients' stories
- We must see our patients beyond their pathology to truly care for them

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## THANK YOU!

AAO Medical Humanities SIG

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