# Lessons Learned from the *Coping with Cancer* Cohort Studies

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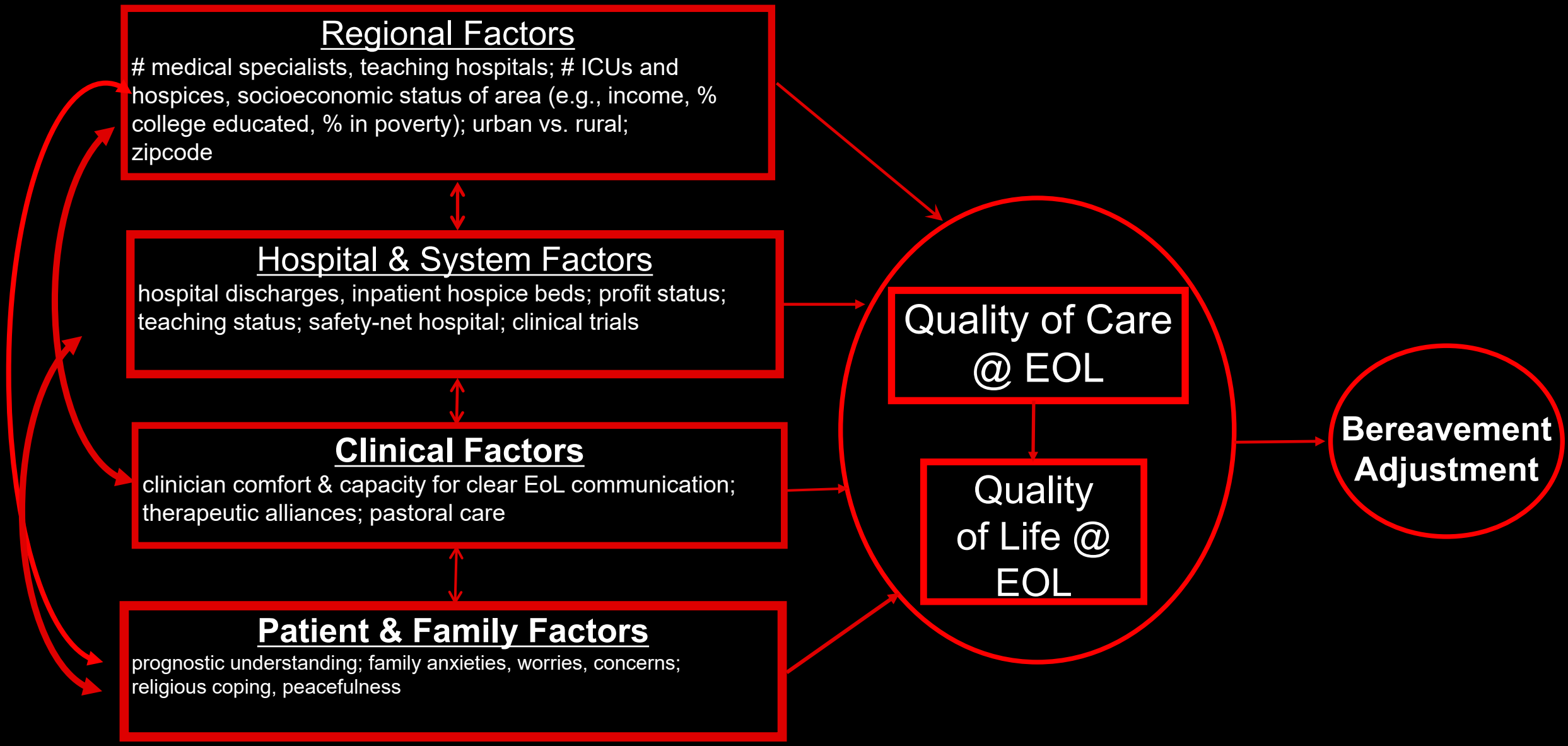
# Our NIH-funded *Coping with Cancer* cohort studies have revealed…

- That EoL outcomes are largely the result of psychosocial forces, such as:

  - What patients & their family caregivers *hear*, or *don't hear*, about the patient's *prognosis* & *treatment options*
  - *Psychological acceptance* of patient's terminal illness
  - Support of *religious beliefs* & *spirituality*
  - *Therapeutic bonds* with healthcare providers

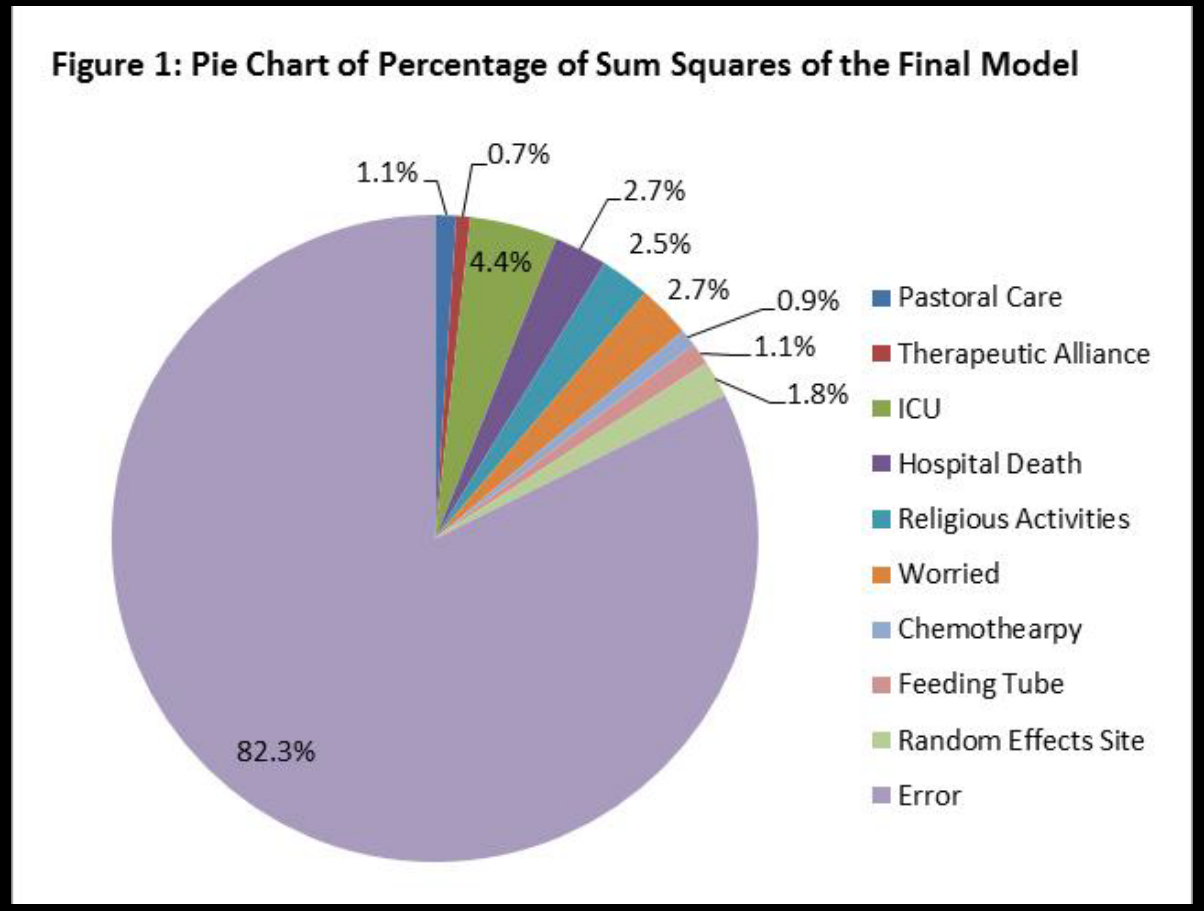
# Coping with Cancer (CwC) revealed *clinical* & *interpersonal* factors as important influences on EoL outcomes



# Factors important to patients' quality of life at the end of life

Zhang B, Nilsson ME, Prigerson HG

*Arch Intern Med.* 2012




| Independent Variable | % Variance Explained in QoL at the EoL |
|---|---|
| 1. ICU stays [a] | 4.4% |
| 2. Hospital deaths [a] | 2.7% |
| 3. Worried patient [b] | 2.7% |
| 4. Religious activities [b] | 2.5% |
| 5. Random Effects of Site | 1.8% |
| 6. Feeding tubes [a] | 1.1% |
| 7. Pastoral care [b] | 1.1% |
| 8. Chemotherapy [a] | 0.9% |
| 9. Therapeutic alliance [b] | 0.7% |
| 10. Error | 82.3% |

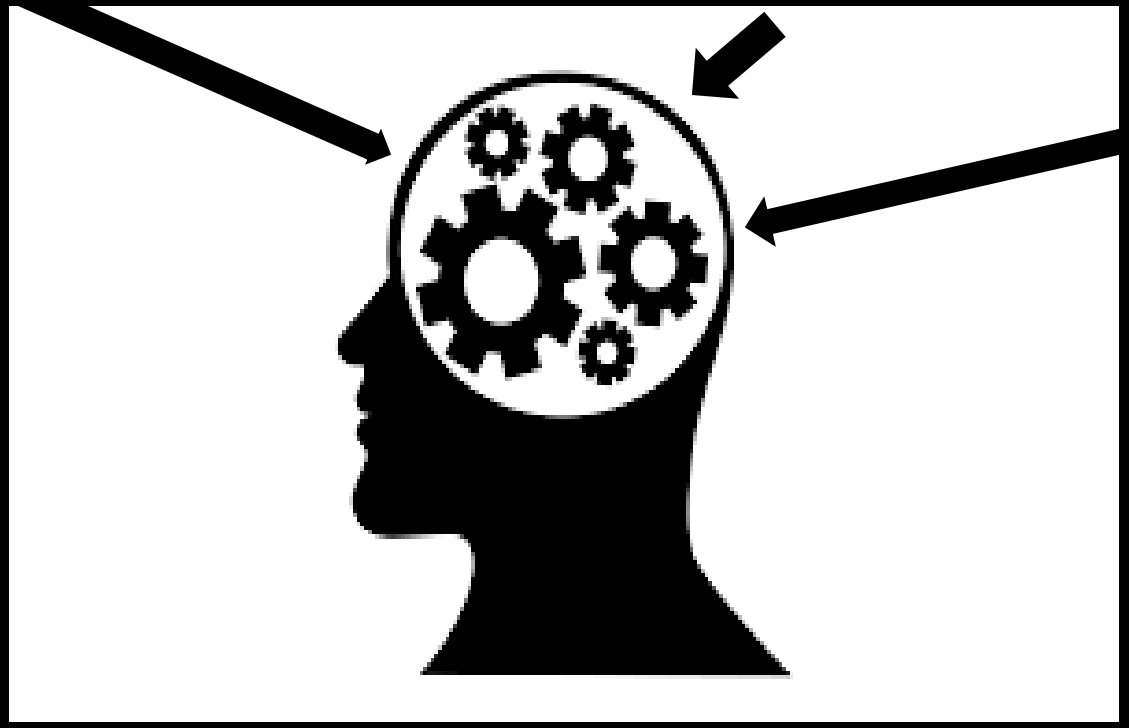
# Psychological Responses to Dying & Death

Common **psychological responses** to death & dying

depression

anxiety

grief



for **dying patients**, their **family caregivers**, and **bereaved survivors**

# Dying Patient Psychological Distress in ICU (N=233)

## Results ~ for caregivers

| Psychological Symptom | % |
|---|---|
| *Moderate-extreme stress* | 50% |
| 1st 48 hrs most stressful time | 46.2% |
| Pain or discomfort severe | 35% |
| Anxious or depressed | 40% |
| **Tense or wound-up** | 93% |
| Frightened that something awful is about to happen | 30% |
| **Worrying** thoughts go through my mind a great deal or a lot | 60% |
| Get a frightened feeling like butterflies in the stomach | 50% |
| Sudden feelings of **panic** | 60% |
| Moments of losing track of what was going on. **Blanked-out** or spaced out | 60% |

| Psychological Symptom | % |
|---|---|
| Feeling on automatic pilot | 50% |
| Sense of time changed; feeling like things in slow motion | 60% |
| Things seemed unreal, like a dream | 60% |
| Surprised that things happened at the time that I was unaware of | 50% |
| **Confused;** there were moments when I had difficulty making sense of what happened | 80% |
| **Felt helpless** | 85% |
| **Sadness and grief** | 100% |
| **Frustrated and angry** | 100% |
| Guilty and ashamed of emotional reactions | 60% |

# Psychological responses to loss over time

**Kubler-Ross' /Bowlby's Stage Theory of Grief: Disbelief, Anger, Bargaining, Depression, Acceptance**

**Disbelief**

**"deer in headlights"**
**shocked/stunned**

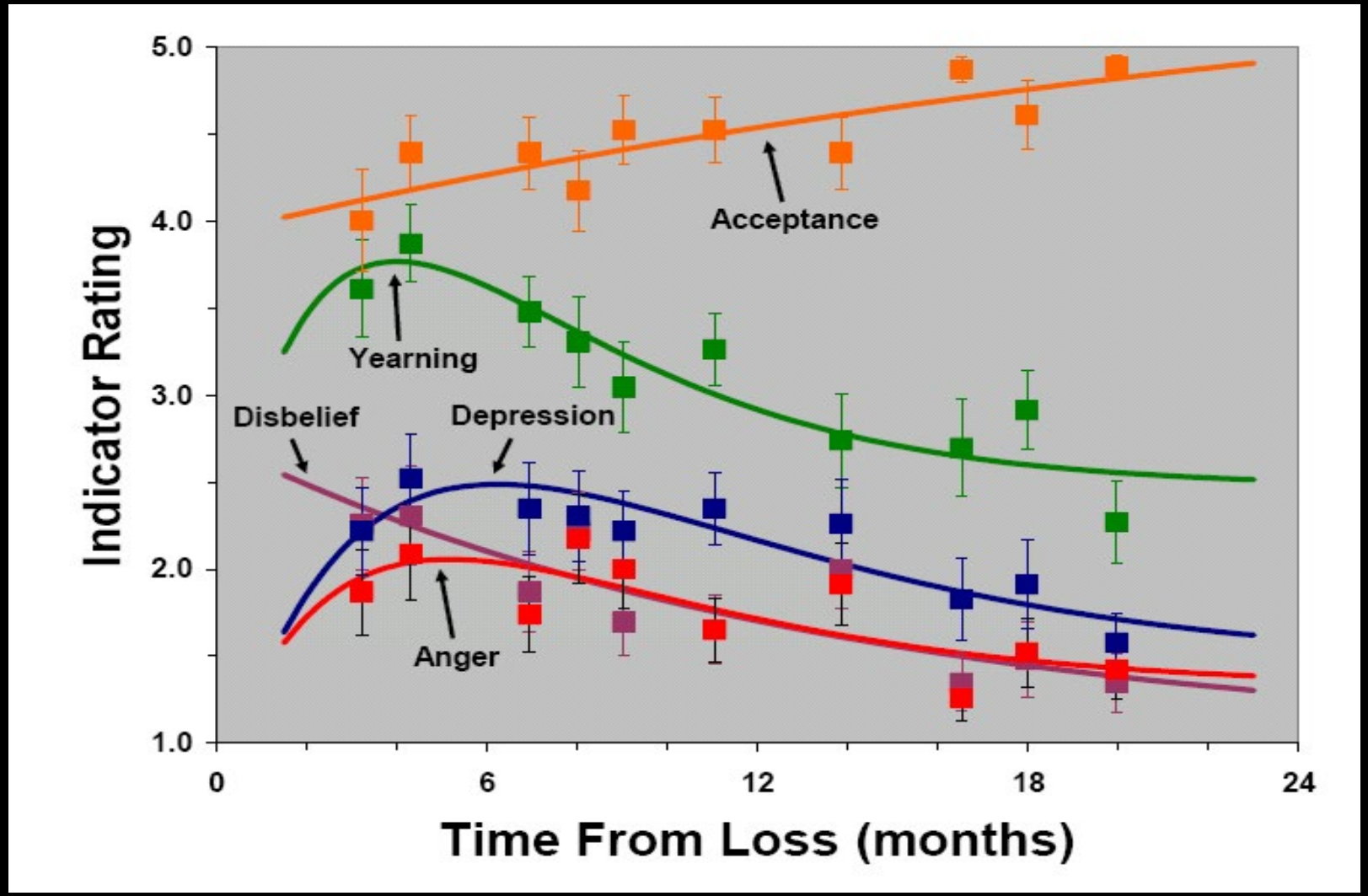
**Anger**

**Bargaining**

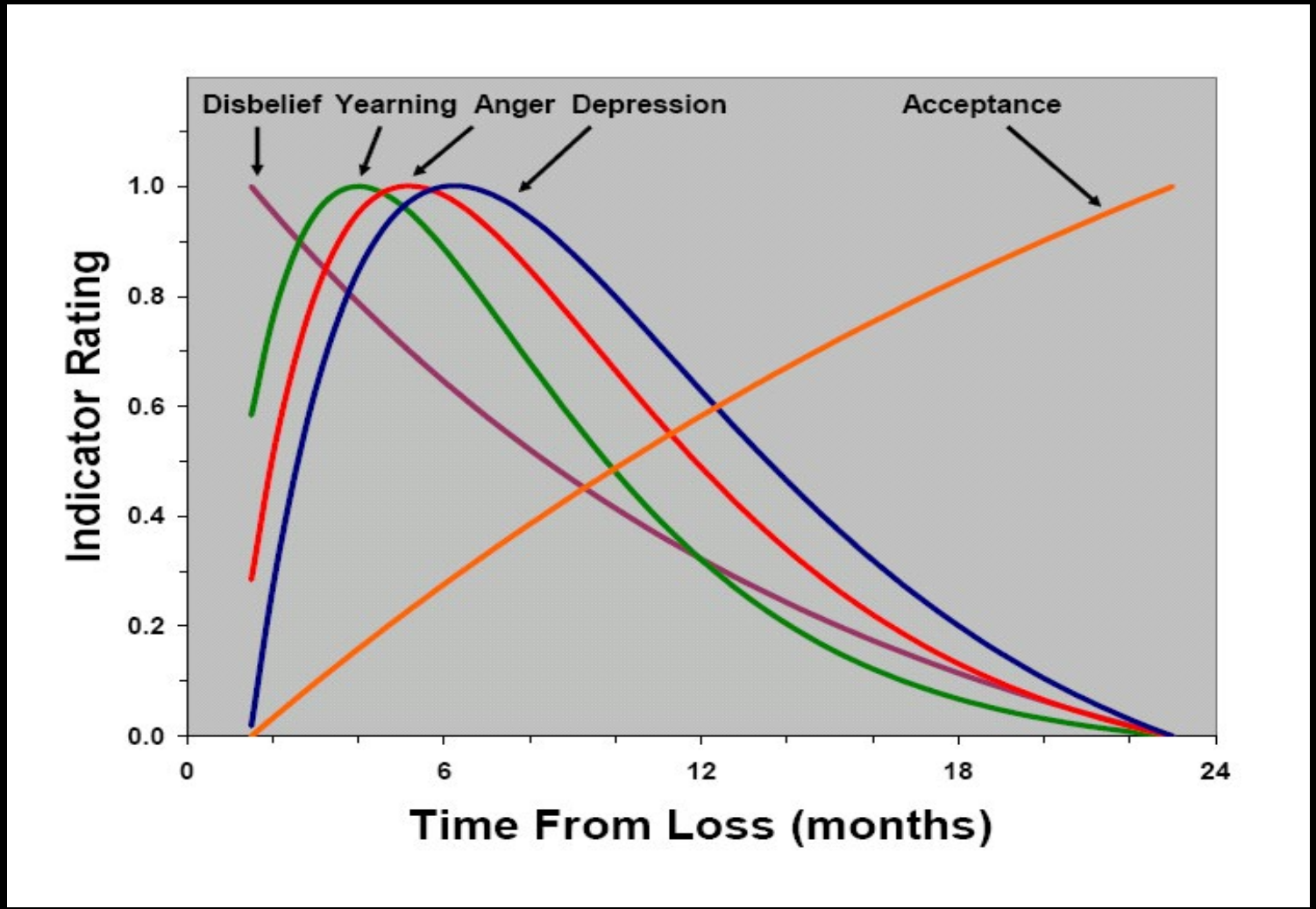
**Depression**

**Acceptance**

**"frog in boiling water"/resignation**
**"back in the saddle"/reintegration**

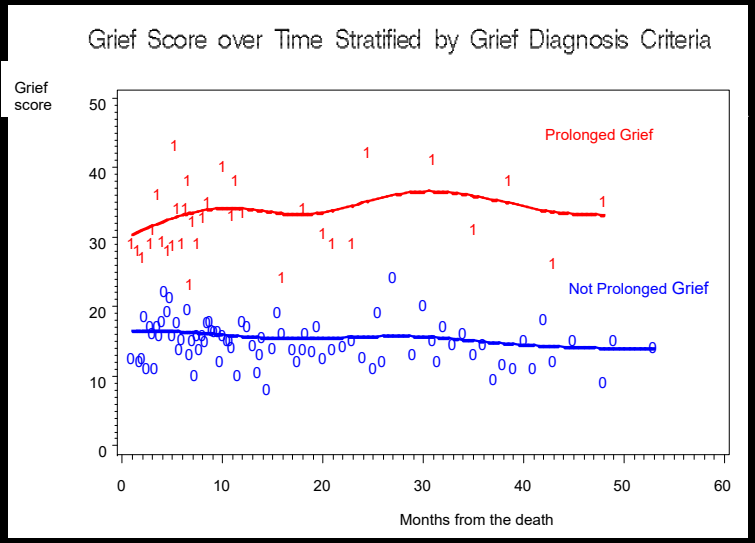



Maciejewski, Zhang, Block, Prigerson JAMA 2007


Disbelief
Yearning
Anger
Depression
Acceptance
Indicator Rating
1.0
0.8
0.6
0.4
0.2
0.0
0
6
12
18
24
Time From Loss (months)

But that's normal/typical/average grief resolution

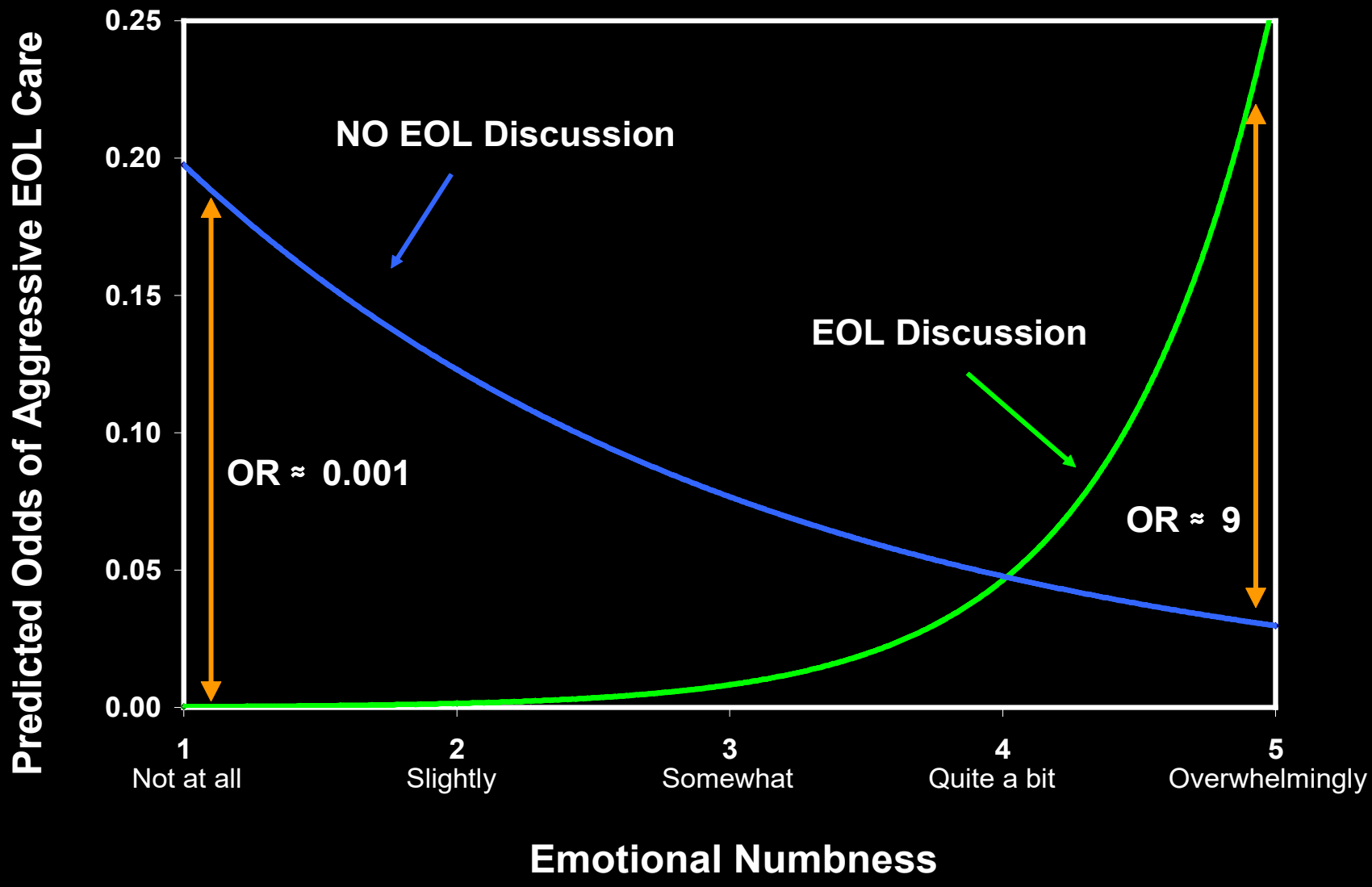
Some bereaved peop n intense, disabling state of grief -->



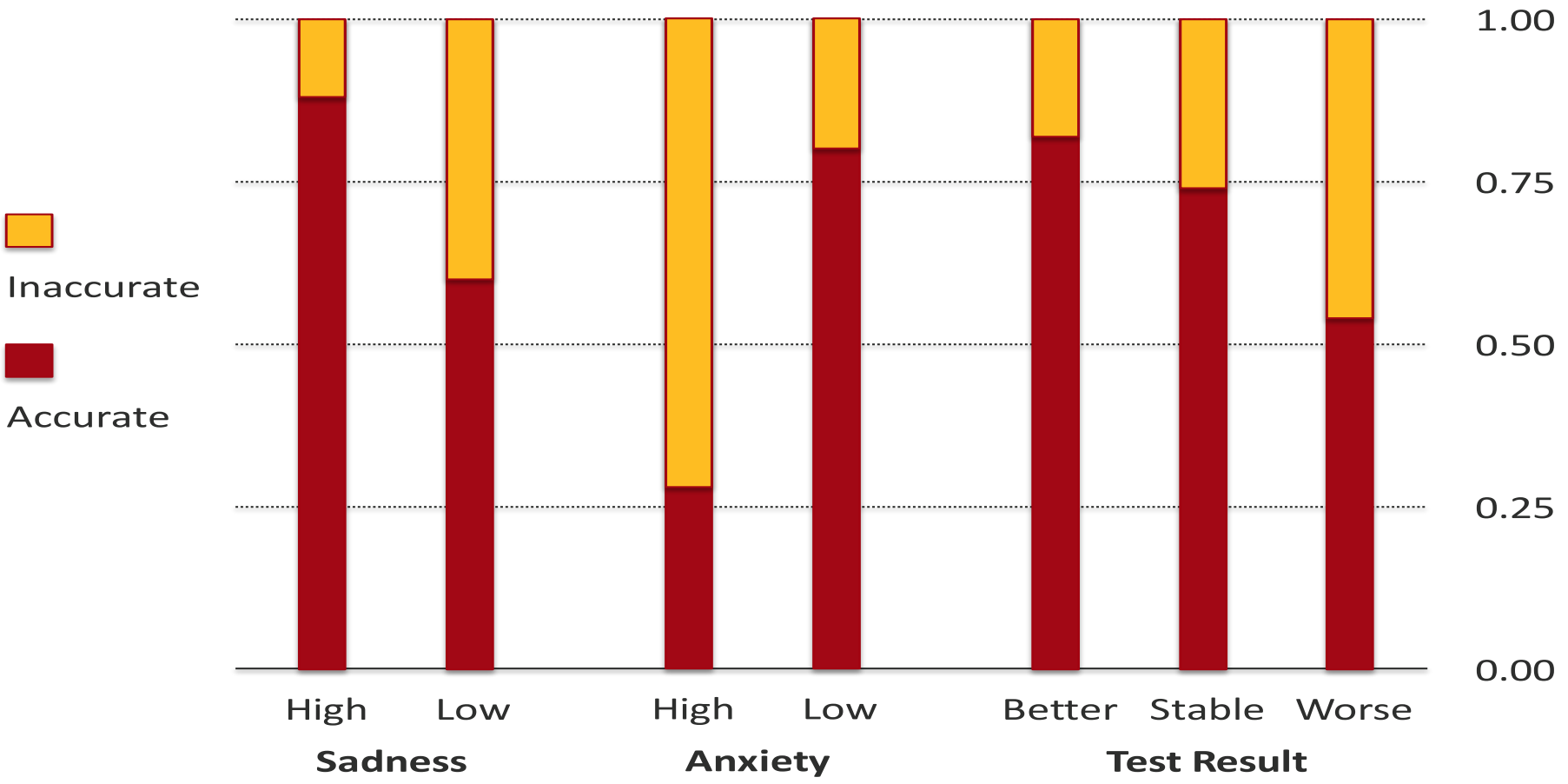
# Hypothesis:

Grieve Us Alone – when *not* to have an EoL discussion

High levels of *grief – psychological numbness* -- will *interfere with patients' processing of EoL discussions, reducing effects on EoL care received*


Predicted Odds of Aggressive EOL Care
0.25
0.20
0.15
0.10
0.05
0.00
NO EOL Discussion
EOL Discussion
OR ≈ 0.001
OR ≈ 9
1
Not at all
2
Slightly
3
Somewhat
4
Quite a bit
5
Overwhelmingly
Emotional Numbness

Anxiety undermines accuracy of understanding prognosis, especially in the context of bad news

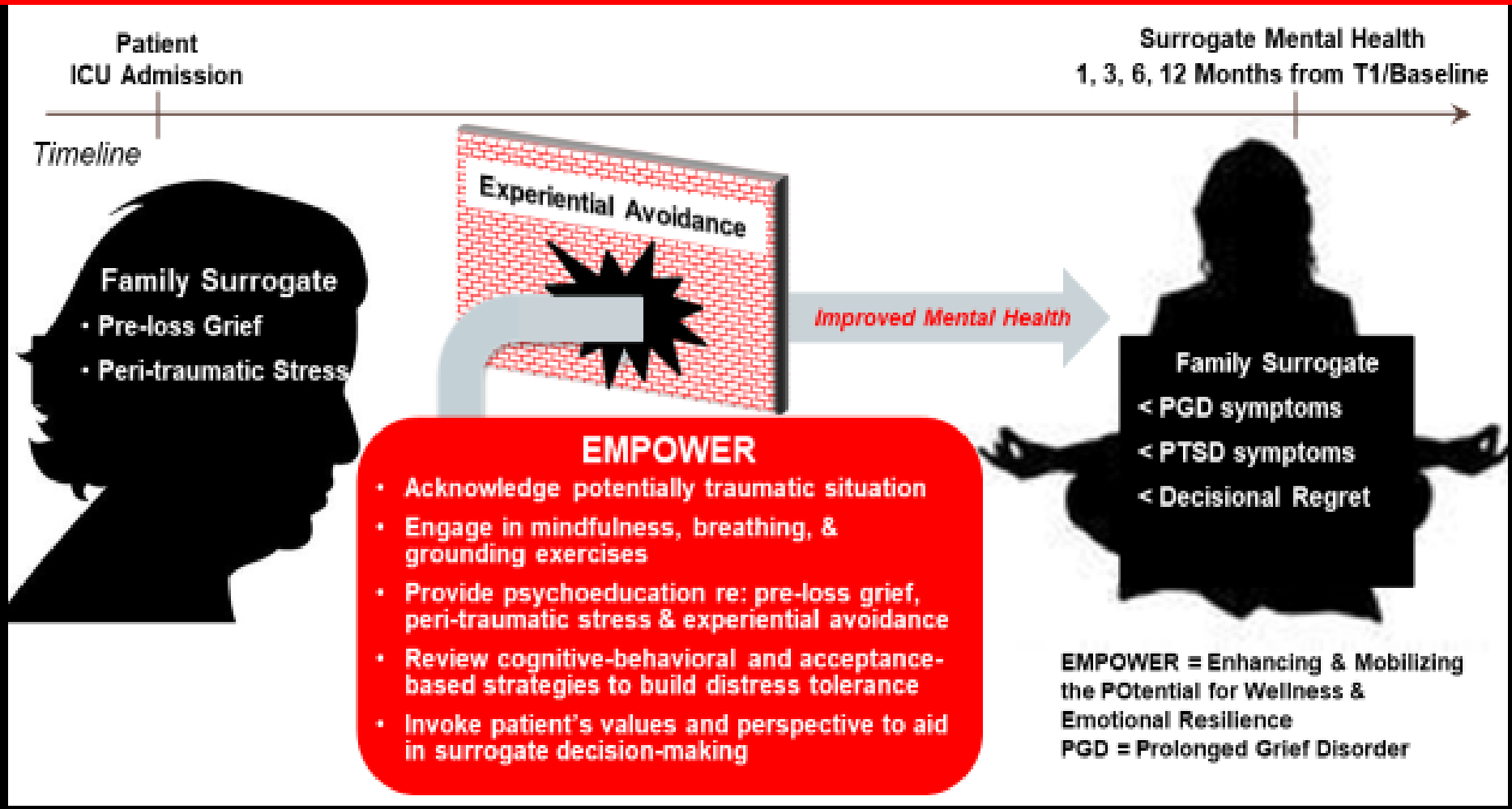



Derry et al. *Journal of Palliative Medicine 2019*

*Take-home Message:*

*Need to address psychological states (grief, anxiety, trauma) to improve EoL outcomes*

# Our EMPOWER intervention aims to improves EoL outcomes for patients and surrogates *by addressing psychological distress*




*The goal is not to eliminate grief, anxiety, and peritraumatic stress reactions, but rather to* ***empower*** *surrogates to respond to these reactions adaptively and compassionately*

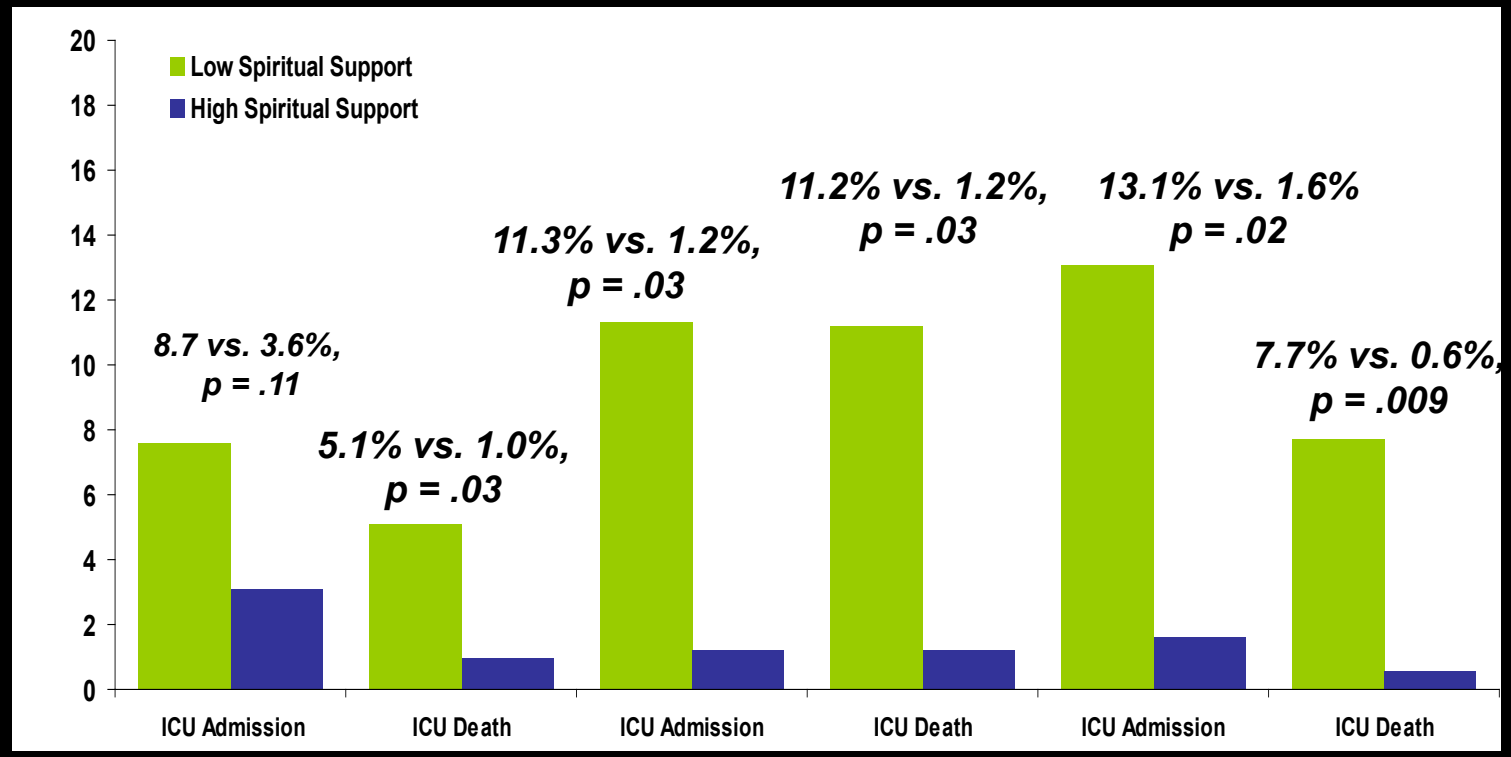
# Preliminary Results

| Measure | Post-intervention | | One-month Follow-up | | Three-month follow-up | |
|---|---|---|---|---|---|---|
| | n | Cohen's d | n | Cohen's d | n | Cohen's d |
| **Grief Intensity (PG-12/13)** | 20 | Large | 16 | Large | 15 | Large |
| **State Anxiety (STAI)** | 16 | Moderate | 11 | Not maintained | 10 | Not maintained |
| **Depression (PHQ-9)** | - | - | 17 | Large | 17 | Moderate-Large |
| **Peritraumatic Distress (PDI)** | 17 | No effect | 12 | No effect | 11 | Small |
| **Traumatic Stress (IES-R)** | 11 | Small-Moderate | 10 | Large | 10 | Large |
| **Experiential Avoidance (BEAQ)** | 25 | Small | 18 | Large | 18 | Large |
| **Decision Regret (DRS)** | 8 | Large | 8 | Moderate-Large | 6 | Large |

# CwC also revealed that spiritual needs of dying patients need to be better addressed:

- Our research found that…
  - 88% advanced cancer patients report religious/spiritual (R/S ) at least somewhat important to them
  - Most (72%) say their R/S needs have ***not*** been met by the care team
  - Support of R/S needs may especially benefit religious, patients, including **black patients**

# Spiritual care from healthcare team reduces intensive care at EoL




Total Sample (n = 303)

Racial/ethnic Minorities (n = 118)

High Religious Coping Patients (n = 159)

*Balboni et al. Cancer, 2011*

- **Conclusion:**

  Need to address spiritual care needs of dying patients & family members

- Informed our Divine Intervention Study

# Future Directions:

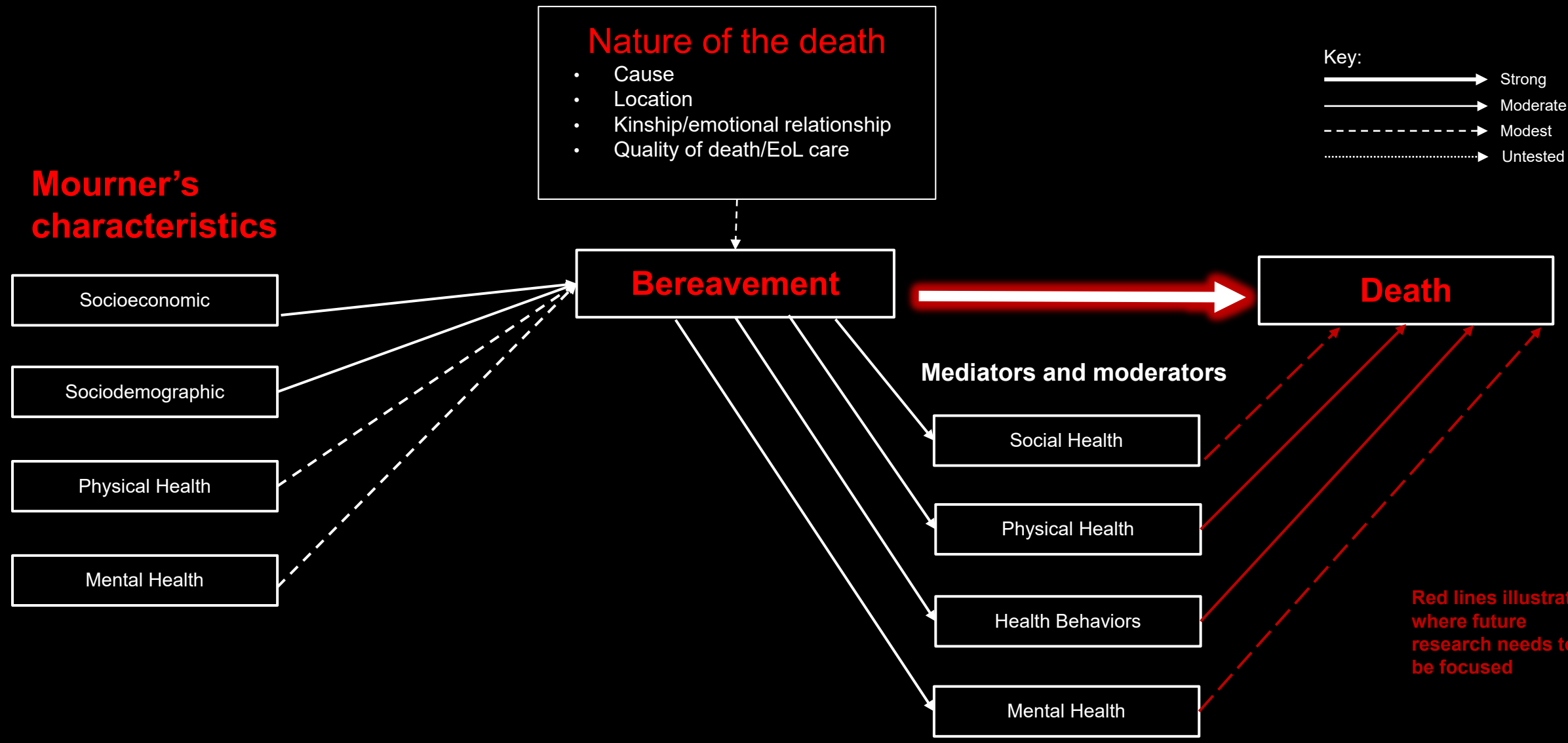
## Bereavement poses significant risk of adverse mental & physical health & death

- Review of evidence demonstrates that bereavement heightens risk of:
  - Mental & physical impairment
  - Death

- Cohort studies are needed to understand the ways in which mental & physical health affect risk of death

- In addition to psychological risks (e.g., “psychogenic death”;“dying of a broken heart”), we hypothesize that “social health” -- that is, social support & integration -- may protect mourners

# Figure 1. Examining the Impact of Bereavement on Death



# Background characteristics: Sociodemographic

**Scorecard: Total= 7**

| Significant Results | Equivocal | Negative Results |
|---|---|---|
| 7 | 0 | 0 |

**Link to literature:**
https://docs.google.com/spreadsheets/d/1W4GFwi8tjbG99WzkFRykkiTYoOLrHD6edtA0Cqz-6Hc/edit?usp=sharing

Home

# Background characteristics: Socioeconomic

**Scorecard: Total= 6**

| Significant Results | Equivocal | Negative Results |
|---|---|---|
| 4 | 2 | 0 |

**Link to literature:**
https://docs.google.com/spreadsheets/d/1W4GFwi8tjbG99WzkFRykkiTYoOLrHD6edtA0Cqz-6Hc/edit?usp=sharing

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# Background characteristics: Physical Health

**Scorecard: Total= 3**

| Significant Results | Equivocal | Negative Results |
|---|---|---|
| 2 | 1 | 0 |

**Link to literature:**

https://docs.google.com/spreadsheets/d/1W4GFwi8tjbG99WzkFRykkiTYoOLrHD6edtA0Cqz-6Hc/edit?usp=sharing

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# Background characteristics: Mental Health

**Scorecard: Total= 1**

| Significant Results | Equivocal | Negative Results |
|---|---|---|
| 1 | 0 | 0 |

**Link to literature:**

https://docs.google.com/spreadsheets/d/1W4GFwi8tjbG99WzkFRykkiTYoOLrHD6edtA0Cqz-6Hc/edit?usp=sharing

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# Bereavement and Mortality

**Scorecard: Total= 40**

| Significant Results | Equivocal | Negative Results |
|---|---|---|
| 36 | 2 | 2 |

**Link to literature:**

https://docs.google.com/spreadsheets/d/1W4GFwi8tjbG99WzkFRykkiTYoOLrHD6edtA0Cqz-6Hc/edit?usp=sharing

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# Mediator/Moderator: Physical Health

**Scorecard: Total= 8**

| Significant Results | Equivocal | Negative Results |
|---|---|---|
| 5 | 1 | 2 |

**Link to literature:**
https://docs.google.com/spreadsheets/d/1W4GFwi8tjbG99WzkFRykkiTYoOLrHD6edtA0Cqz-6Hc/edit?usp=sharing

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# Mediator/Moderator: Mental Health

**Scorecard: Total= 6**

| Significant Results | Equivocal | Negative Results |
|---|---|---|
| 4 | 2 | 0 |

**Link to literature:**
https://docs.google.com/spreadsheets/d/1W4GFwi8tjbG99WzkFRykkiTYoOLrHD6edtA0Cqz-6Hc/edit?usp=sharing

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# Mediator/Moderator: Health Behaviors

**Scorecard: Total= 6**

| Significant Results | Equivocal | Negative Results |
|---|---|---|
| 5 | 1 | 0 |

**Link to literature:**

https://docs.google.com/spreadsheets/d/1W4GFwi8tjbG99WzkFRykkiTYoOLrHD6edtA0Cqz-6Hc/edit?usp=sharing

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# Mediator/Moderator: Social Health

**Scorecard: Total= 2**

| Significant Results | Equivocal | Negative Results |
|---|---|---|
| 1 | 1 | 0 |

**Link to literature**

https://docs.google.com/spreadsheets/d/1W4GFwi8tjbG99WzkFRykkiTYoOLrHD6edtA0Cqz-6Hc/edit?usp=sharing

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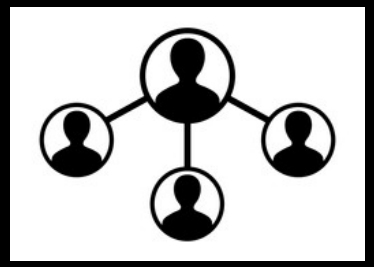
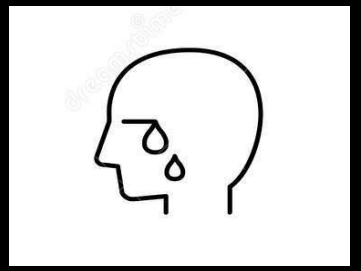
# Figure 1. A Conceptual Model Relating the Satisfaction of Social Needs to Bereavement Adjustment

**Bereavement** **Social Needs** **Adaptation to Loss**





**Mourner**

**Social Deprivations**

Lost sense of:

- Belonging and connectedness to others
- Caring and nurturance of others
- Safety and security evoked by others
- Identity and role clarification in relation to others
- Feeling understood by other
- Feeling appreciated, valued, and loved by others
- Appreciating, valuing, and loving others

**Bereavement Outcomes**

- Mental health
  - Prolonged Grief Disorder
  - Suicidal Thoughts & Behaviors

## Conclusions: Cohort Studies like CwC have identified:

1. The role of **mental health** in EoL decision-making, care, quality of life/death

2. The role of **spiritual care** (e.g., healthcare chaplains) in:
   a. addressing unmet spiritual needs
   b. promoting peaceful acceptance of terminal illness
   c. promoting better EoL care
   *d. potentially* reducing racial/ethnic disparities in EoL outcomes

3. The influence of **social support**/integration on reducing mourner's risk of:
   a. psychological distress (eg, PGD, suicidal thoughts & behaviors)
   b. physical dysfunction & disorders
   c. death

Acknowledge many colleagues include Paul Maciejewski, Wendy Lichtenthal, Madeline Rogers.  Special thanks to Hillary Winoker for review of the bereavement->mortality literature.

# The End

# Conclusion:

Need to address spiritual care needs of dying patients & family members