

*Families Confronting the End-of-Life:  
Promoting **Peaceful Acceptance** of Death*

Holly G. Prigerson, PhD

Director, Center for Psycho-oncology  
& Palliative Care Research  
Dana-Farber Cancer Institute  
Associate Professor of Psychiatry  
Brigham & Women's Hospital  
Harvard Medical School

# Overview

Conceptual Model: Predictors, correlates & outcomes of **peaceful acceptance** at the end-of-life (EOL)

Defining terms:

1. **Acceptance** – cognitive; emotional
2. **Grief** – normal; Prolonged Grief Disorder
3. **States of Grief** – changes over time

Preliminary Test of **PEACE** Model

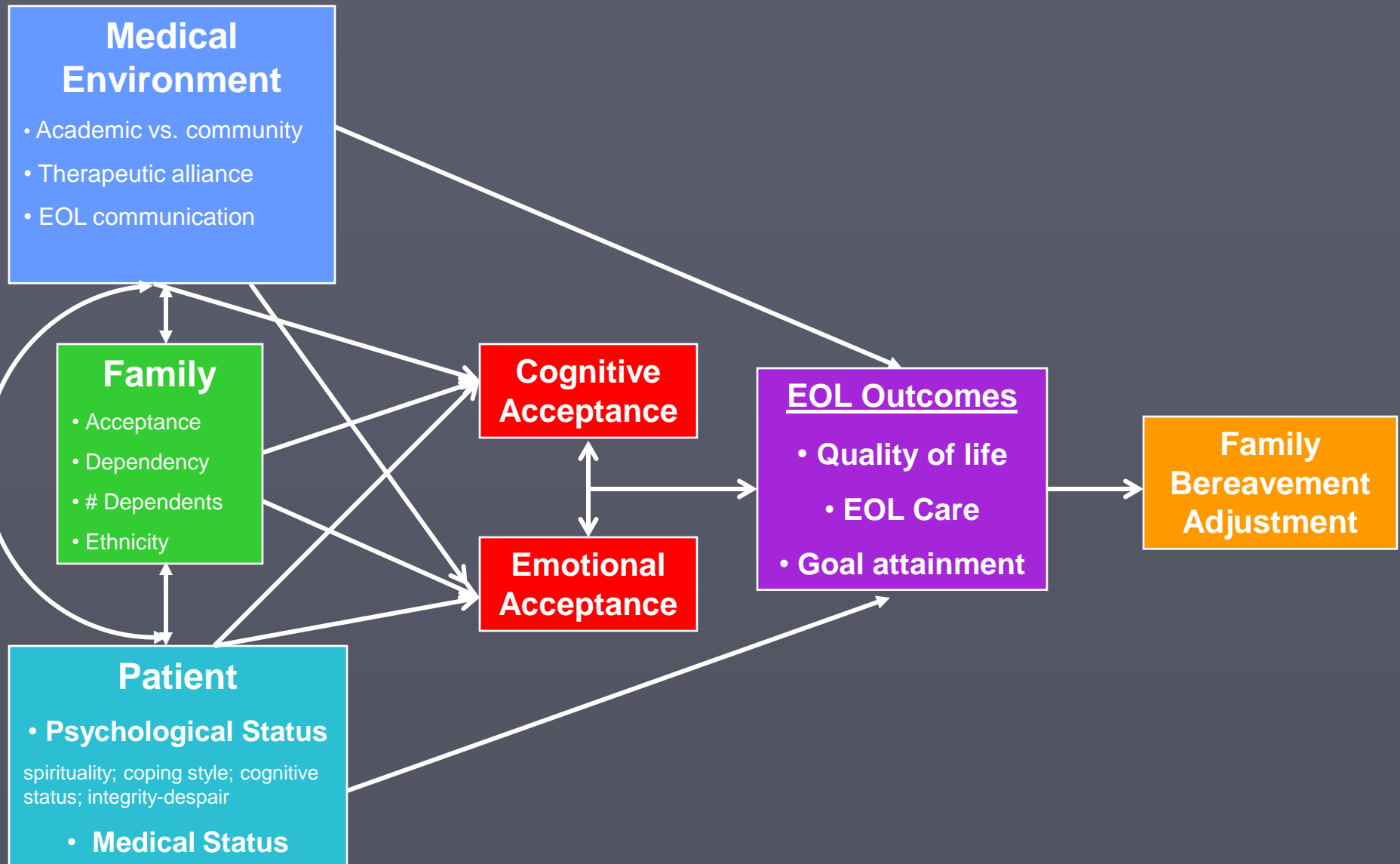
Promoting acceptance in family members

# Promoting End-of-Life Acceptance in the Cancer Experience (**PEACE**):

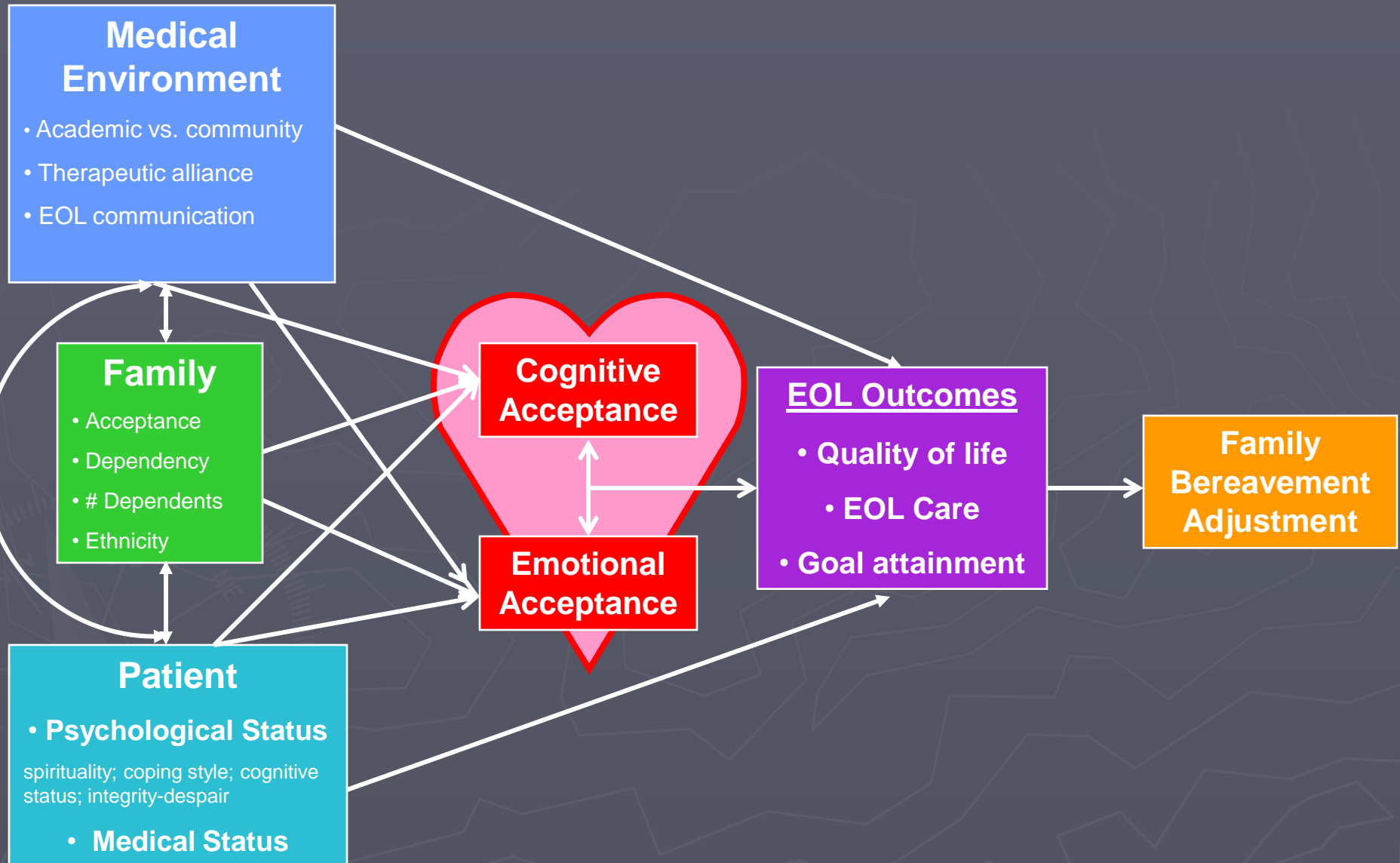
## The **PEACE** Model

*preliminary results from our **Coping  
with Cancer** data (MH63892; CA10637)*

# The PEACE Model



# The PEACE Model



# End of Life Acceptance

- *Cognitive acceptance* : awareness that patient is terminally ill (< 6 mos life-expectancy)
- *Emotional acceptance (peacefulness)* : the ability to be at peace with, rather than struggle against, the terminal prognosis

# Peace, Equanimity and Acceptance in the Cancer Experience (**PEACE**) Scale (Cronbach's $\alpha$ = .86)

1. To what extent are you able to *accept your diagnosis of cancer*?
2. To what extent would you say you have a *sense of inner peace* and harmony?
3. To what extent do you feel that you have *made peace with your illness*?
4. Do you feel *well-loved now*?
5. To what extent do you feel a sense of *inner calm and tranquility*?
6. To what extent do *changes in your physical appearance upset you*?
7. To what extent does *worry about your illness* make it difficult for you to live from day to day?
8. To what extent do you feel that it is *unfair* for you to get cancer now?
9. To what extent do you feel that your *life, as you know it, is now over*?
10. To what extent do you feel *angry* because of your illness?
11. To what extent do you think your illness has *beaten you down*?
12. To what extent do you feel *ashamed* of, or embarrassed by *your current condition*?

# Cognitive & Emotional Acceptance

<p>N = 476 r = -0.097</p>	<p><b>Cognitive Acceptance</b> Yes (32%)</p>	<p><b>Cognitive Acceptance</b> No (68%)</p>
<p><b>Emotional Acceptance:</b> Feel peaceful (67%)</p>	<p>94 19.75% of total <u>61% of "aware" are at peace</u></p>	<p>228 47.9% of total <u>71% of "unaware" are at peace</u></p>
<p><b>Emotional Acceptance:</b> Don't feel peaceful (33%)</p>	<p>60 12.6% of total</p>	<p>94 19.75% of total</p>



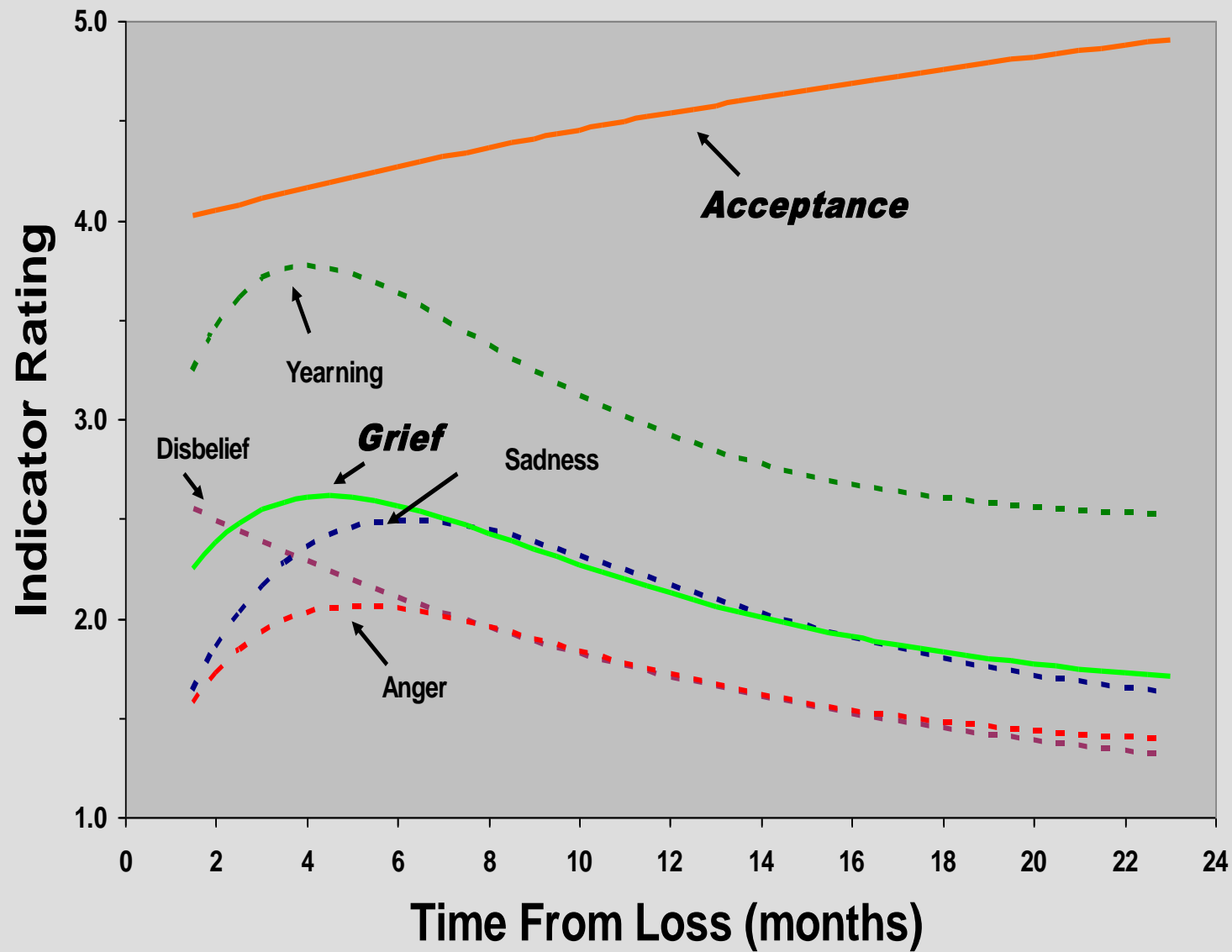
# Cognitive & Emotional Acceptance (Peace Item)

Patient Mental Health & Spirituality	Cognitive Acceptance (p-value)	Emotional Acceptance (p-value)
MDD dx (OR)	1.28 (0.50)	<i>0.88 (0.03)</i>
GAD dx (OR)	0.46 (0.32)	0.62 (0.29)
Terrified ( $\beta$ )	<i>0.13 (0.003)</i>	<i>-0.65 (&lt;0.0001)</i>
Sad ( $\beta$ )	<i>0.11 (0.02)</i>	<i>-0.55 (&lt;0.0001)</i>
Life as gift ( $\beta$ )	<i>-0.10 (0.03)</i>	<i>0.48 (&lt;0.0001)</i>
Death anxiety ( $\beta$ )	0.05 (0.66)	--
Spirituality ( $\beta$ )	-0.11 (0.06)	<i>0.43 (0.02)</i>

# Grief & Acceptance: Opposite Sides of the Same Coin

(Prigerson & Maciejewski, *Br J Psychiatry*, 2008)

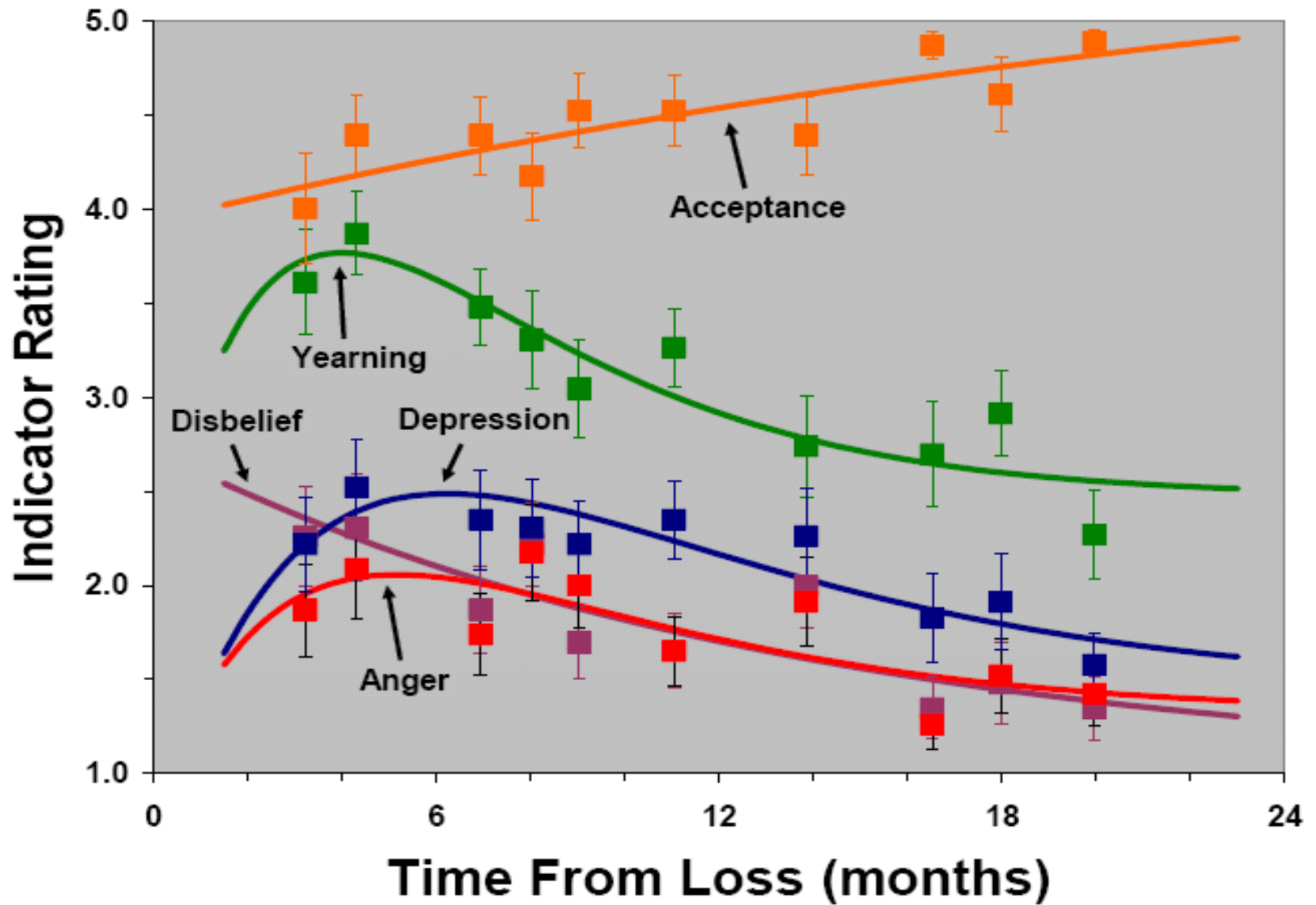
- *Emotional acceptance of loss* = letting go of wanting; ceasing to struggle against approaching death
- *Grief* = wanting what you can't have



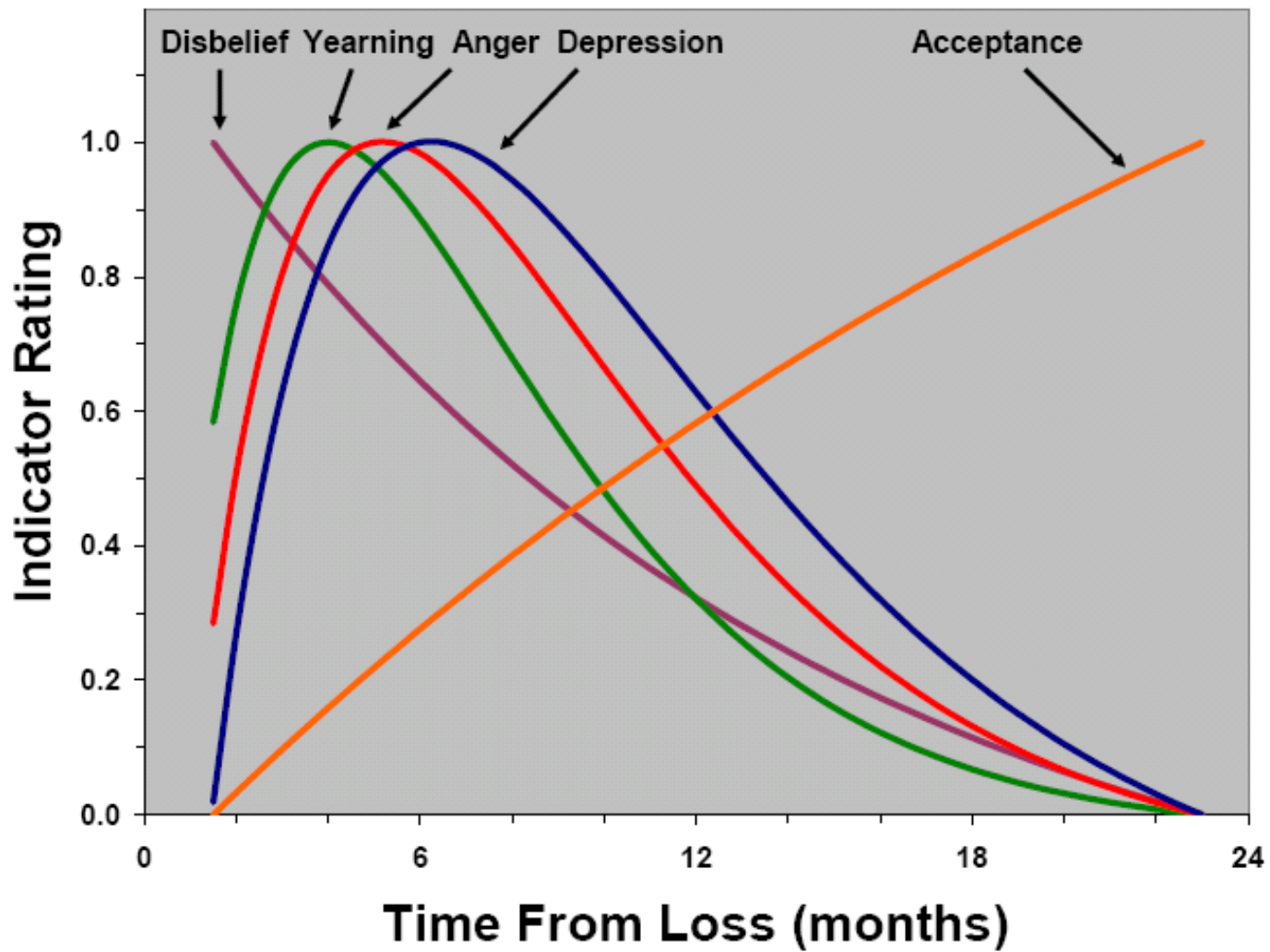
As family members process the loss, an inability to resolve grief creates instability in the family system...

How does the course of **normal grief** differ from that of **prolonged grief**?

- **Normal grief** resolves over time from loss (80-90%)
- Untreated, **Prolonged Grief Disorder** symptoms persist (10-20%)



Maciejewski, Zhang, Block, Prigerson, *JAMA* 2007



Maciejewski, Zhang, Block, Prigerson, *JAMA* 2007

# Criteria for **Prolonged Grief Disorder** Proposed for DSM-V and ICD-11

**Criterion A.** Loss of a significant other

**Criterion B. Separation Distress:** yearning (e.g., craving, pining, or longing for the deceased; physical or emotional suffering as a result of the desired but unfulfilled reunion with the deceased) daily or to a disabling degree

**Criterion C. Cognitive, Emotional, and Behavioral Symptoms:** The bereaved person must have  $\geq 5$  below symptoms experienced daily or to a disabling degree.

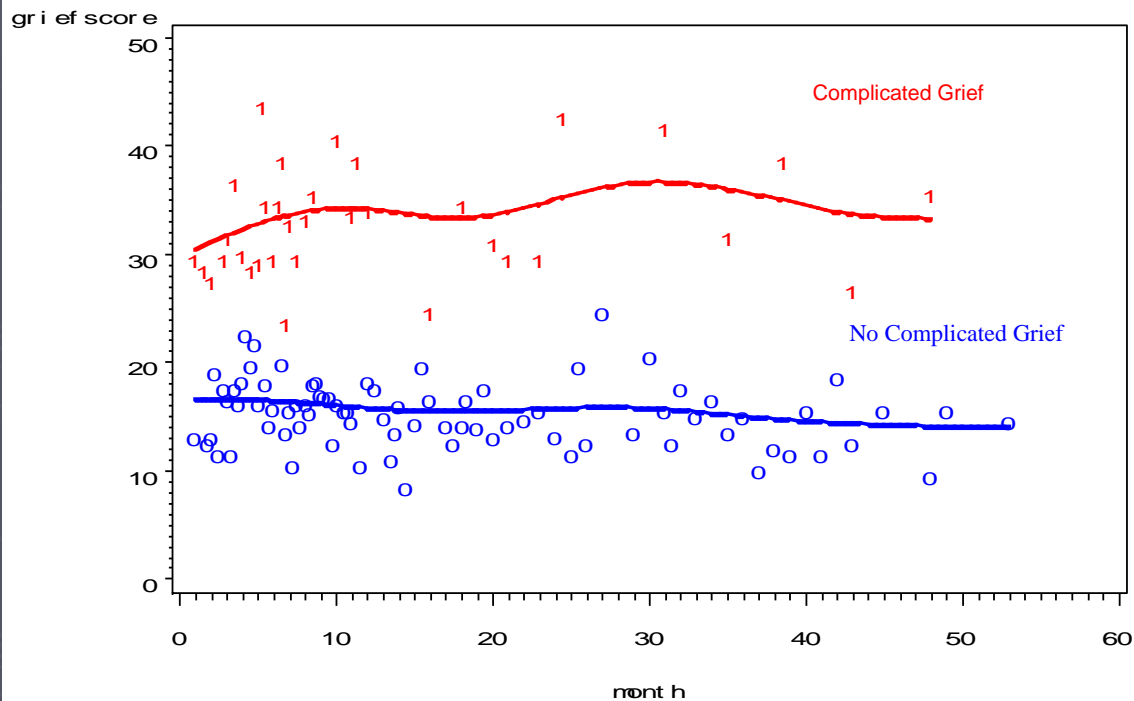
1. Confusion about one's role in life or diminished sense of self (i.e., feeling that a part of oneself has died)
2. Difficulty accepting the loss
3. Avoidance of reminders of the reality of the loss
4. Inability to trust others since the loss
5. Bitterness or anger related to the loss
6. Difficulty moving on with life (e.g., making new friends, pursuing interests)
7. Numbness (absence of emotion) since the loss
8. Feeling that life is unfulfilling, empty, and meaningless since the loss
9. Feeling stunned, dazed or shocked by the loss

**Criterion D. Timing:** Diagnosis should not be made until at least 6 months have elapsed since the death

**Criterion E. Impairment:** The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning (e.g., domestic responsibilities)

# Grief Resolution for those meeting criteria for PGD

Grief Score over Time Stratified by Grief Diagnosis Criteria





## Therapeutic Alliance:

The Human Connection Scale (Cronbach's  $\alpha=.90$ )

- 16 items measuring: mutual understanding; caring; trust
  - ▶ How much do you feel your doctor cares about you?
  - ▶ How much do you trust your doctor?
  - ▶ How open-minded do you feel your doctor is?
- **Emotional acceptance** ( $r=.31$   $p<.00001$ )
- *Cognitive acceptance n.s.*
- Less time in ICU in last week ( $p=.002$ )

## EOL Discussions & Acceptance

- EOL discussions associated with patient's cognitive acceptance of terminal illness?
  - AOR=2.24, [95% CI 1.45-3.44]
  - (1/3 cog accept; 2/3 don't – so much room for improvement)
- EOL discussions not shown to “take away hope” or adversely affect emotional acceptance/peace?
  - EOL discussions (months before death) were NOT associated with psychological harm

# Dependent children and patient mental health

	with dep child	without dep child	adjusted p-value
Generalized Anxiety Disorder (GAD)	4%	2%	0.20
Major Depressive Disorder (MDD)	11%	7%	0.07
Panic Disorder	9%	2%	0.0004
Worried	3.7 (3.3)	2.9 (3.1)	0.006
Peaceful	60%	70%	0.01

## Dependent children and caregiver mental health

	Caregivers with <b>dep child</b>	Caregivers without <b>dep child</b>	Adjusted p-value
MDD	10%	3%	0.01
GAD	11%	3%	0.02
Panic Disorder	10%	3%	0.05

# Location of Patient Death

	with dep child	without dep child	Adjusted p-value
Home	54%	54%	0.75
Hospital	26%	23%	0.14
ICU	12%	6%	0.74
Inpatient Hospice	1%	14%	0.02

# Quality of Death

- Worse quality of death/last week of life:  
5.51 ( $\sigma=3.21$ ) vs. 6.54 ( $\sigma=2.87$ ) p-  
value:0.04

# Caregiver's Relationship to Dying Patient and Risk for PGD versus MDD

## Marital Quality

	PGD		MDD	
	<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>
➤ feelings of security	.47	.005	.15	ns
➤ dependency on partner	.43	.001	.06	ns
➤ confiding in partner	.43	.001	.02	ns
➤ active emotional support	.60	.0001	.18	ns
➤ combo security, confiding, support	.69	.0001	.23	ns
➤ Overall Quality of Marriage	.39	.01	.03	ns

# Effects of Cognitive & Emotional Acceptance on EOL Care

- **Cognitive Acceptance** resulted in 2.12 times greater likelihood of using **inpatient hospice**, **goal attainment**, and less time in the **ICU** at EOL (p=0.05)
- **Emotional Acceptance** resulted in significantly less use of aggressive measures (**feeding tubes**) and higher rates of **goal attainment** in the last week of life (p=0.05)



# Cognitive & Emotional Acceptance, “Peaceful Awareness”, associated with...

- Lower rates of psych distress
- Higher rates of ACP
- Better quality of life in last week
- Bereaved caregivers better physical and mental health 6 months post-loss

# Conclusions

## How to promote PEACE?

### Medical Environment

- EOL communication (curability, prognosis, goals of care)
- Therapeutic alliance

### Family

- Promote independence and acceptance
- Ensure safety and security of dependents

### Patient

- Ensure symptom management (pain)
- Spirituality
- Resolve grief
  - spiritual support (pastoral care visits)
  - Social and personal support in confronting death (grief therapy)

# Future Research: The PEACE Study

- **Prospective, longitudinal** cohort study of oncology provider, patient, caregivers
- Documentation (validated with **audio-taping**) to assess the EOL discussion more accurately
- Assess **acceptance pre-post EOL discussions** and over time to determine effect of EOL discussions on acceptance, **change in acceptance**, and **outcomes of acceptance** for **patients** and their **family** members