THE EMPOWER INTERVENTION: ADDRESSING PSYCHOLOGICAL DISTRESS AT THE END-OF-LIFE

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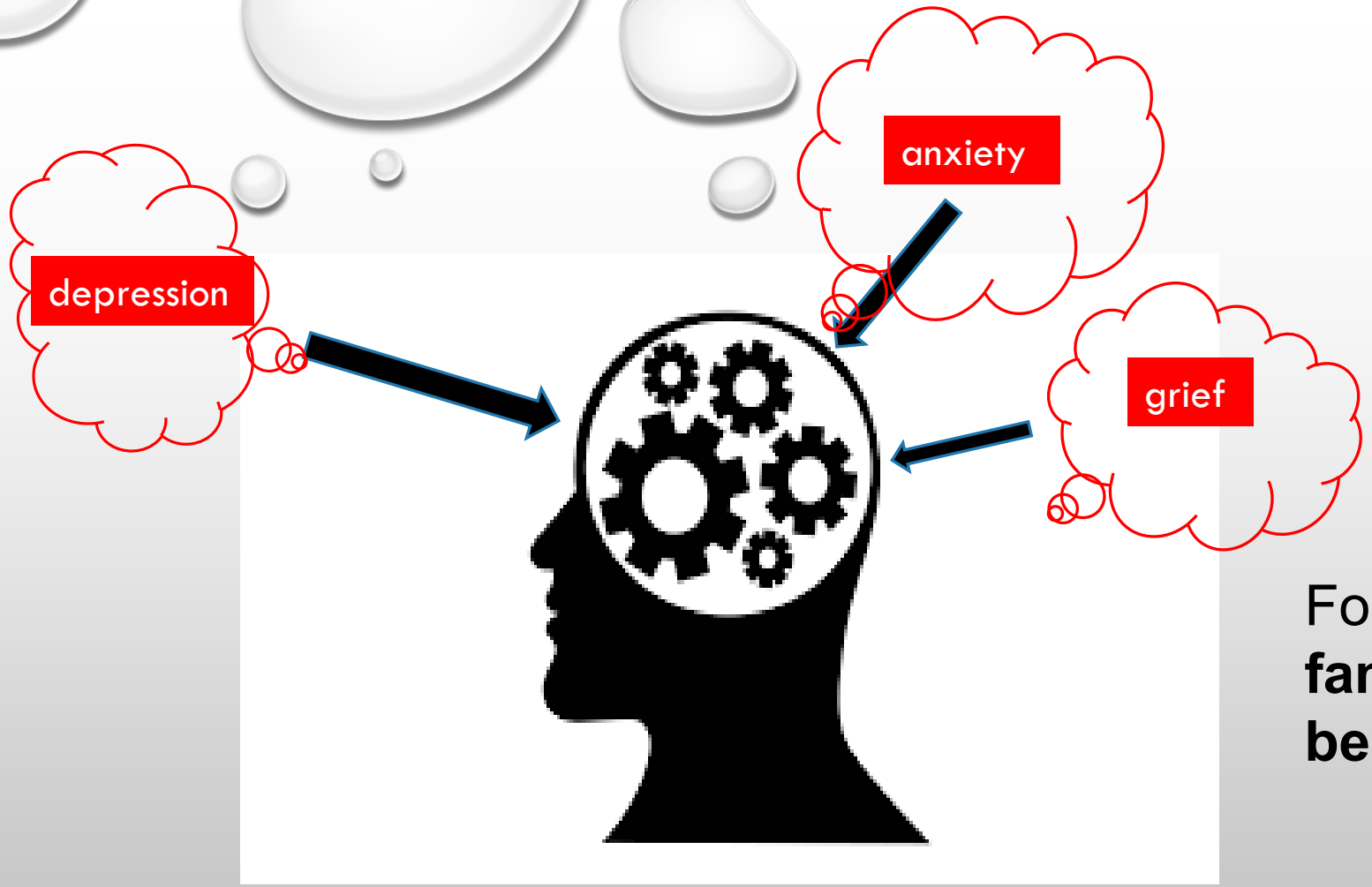
THIS TALK WILL DISCUSS THE FOLLOWING ASPECTS OF MENTAL HEALTH AT THE END-OF-LIFE…

- **PSYCHOLOGICAL RESPONSES** TO SERIOUS ILLNESS, DYING, & DEATH
- **COURSE** OF THESE PSYCHOLOGICAL RESPONSES
- **PREDICTORS & OUTCOMES** OF THESE PSYCHOLOGICAL RESPONSES
- **E**NHANCING & **M**OBILIZING THE **PO**TENTIAL FOR **W**ELLNESS & **E**MOTIONAL **R**ESILIENCE OF FAMILY CAREGIVERS OF DYING PATIENTS (**EMPOWER**) INTERVENTION

Psychological Responses to Serious Illness, Dying, & Death



COMMON **PSYCHOLOGICAL RESPONSES** TO DEATH & DYING

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

Anxiety -- fear, horror, worry
Grief -- yearning, anger, disbelief, emotional numbness
Depression -- sad mood, guilt, helplessness, hopelessness

} **Peritraumatic Distress**

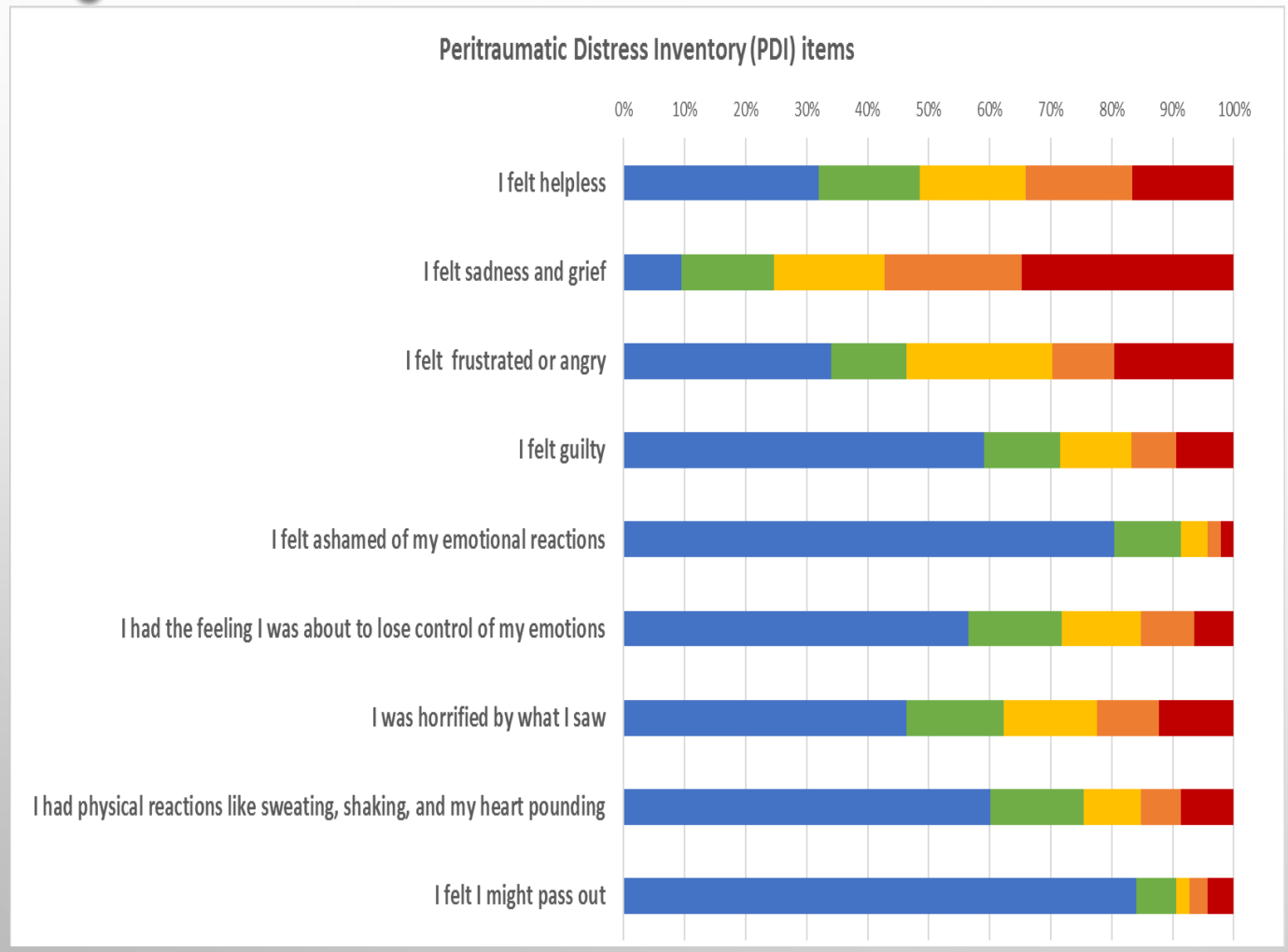
ICU PATIENT PSYCHOLOGICAL DISTRESS

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%

- **ICU patient Peritraumatic Dissociative Experiences Questionnaire (PDEQ) scores predicted IES-R scores Spearman's rho = 0.70, p = 0.02) at 1-month follow-up, suggesting they lead to PTSD post-ICU discharge (Derry et al. 2021) implications for preventing PICS**

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%

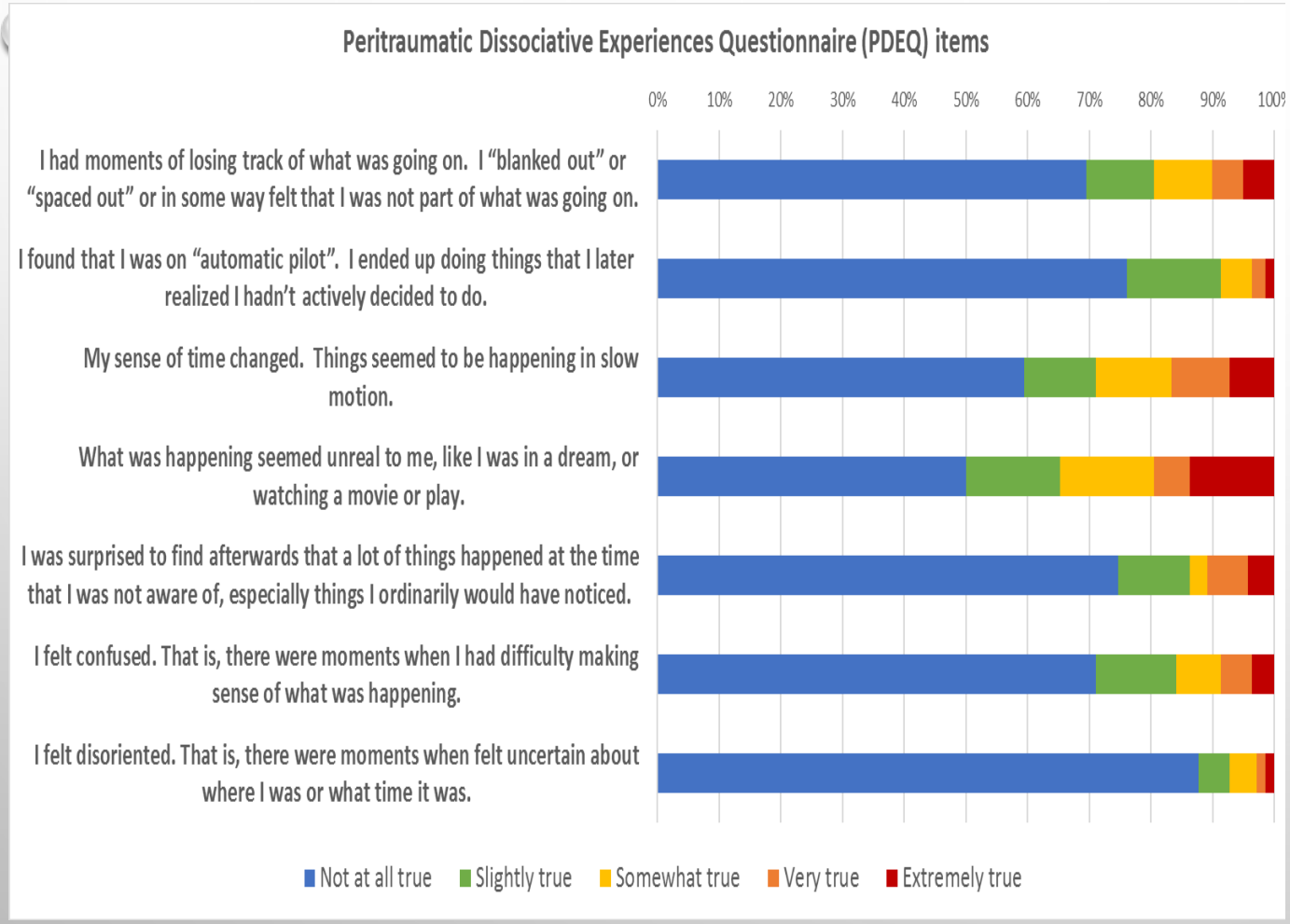
PERI-TRAUMATIC DISTRESS AMONG FAMILY CAREGIVERS OF PATIENTS IN THE ICU (N=138)



PDI items most frequently endorsed as very true or extremely:

- **sadness & grief** (57%)
- **helplessness** (34%)
- **frustration & anger** (30%)

PERI-TRAUMATIC DISSOCIATION IN CAREGIVERS OF PATIENTS IN THE ICU (N=138)



PDEQ items most frequently endorsed as very true or extremely:

- feeling that events seemed **unreal** (20%)
- like they were happening in **slow motion** (17%)

WHAT ARE THE COMMON MENTAL DISORDERS EXPERIENCED BY …

- terminally ill patients
- their family caregivers
- bereaved survivors?

Although psychological sxs common, they *rarely* rise to level of a mental disorder

Table 1. Mental Disorders Among *Advanced Cancer Patients*

Diagnosis	No. (%)
Major Depressive Disorder	17 (7%)
Generalized Anxiety Disorder	8 (3%)
Panic Disorder	12 (5%)
Posttraumatic Stress Disorder	6 (2%)
At least one of above diagnoses	29 (11.6%)

Kadan-Lottick et al. Cancer, 2005

Rates of anxiety disorders higher in caregivers than dying cancer patients

Outcome	% Patients	% (n) Caregivers
Major depressive disorder	7%	7.0 (14)
Generalized anxiety[a]	3%	3.5 (7)
Panic disorder	5%	7.5 (15)
Posttraumatic Stress Disorder	2%	6.0 (12)

Vanderwerker et al. JCO, 2005

Bereaved Caregiver's Mental Health Outcomes

Bereaved Caregivers' Mental Health Outcomes	n	N	% Pre/*Post* Death
PTSD	10	238	**6 / *4***
GAD	4	236	**4 / *2***
PD	9	238	**8 / *4***
MDD	17	239	**7 / 7**
PGD	15	142	**10.6**

At 6 months post-loss

Rates of: anxiety disorders drop, depression remains the same, and PGD most prevalent when caregivers become bereaved

Wright et al. JCO, 2010

WHAT IS PROLONGED GRIEF DISORDER?

- Chronic, intense, distressing reaction to loss distinct from bereavement-related depression and anxiety
- Unlike normal grief, individuals with PGD appear to be "stuck" in their grief, yearning intensely for deceased, emotionally numb/detached, identity disturbance, protesting the reality of the loss
- Prevalence is <5% following normal circumstances of loss

APA Sept 23, 2021 Press release:

PROLONGED GRIEF DISORDER

TIPS FOR UNDERSTANDING THE NEWEST ADDITION TO THE DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS

WHAT IS PGD?

Prolonged grief disorder happens when someone loses someone close, and they experience an intense yearning/longing for or preoccupation with the deceased person. Their bereavement lasts longer than social norms and causes distress or problems functioning.

SYMPTOMS

- Identity disruption (e.g., feeling as though part of oneself has died).
- Marked sense of disbelief about the death.
- Avoidance of reminders that the person is dead.
- Intense emotional pain (e.g., anger, bitterness, sorrow) related to the death.
- Difficulty moving on with life.
- Emotional numbness.
- Feeling that life is meaningless.
- Intense loneliness (i.e., feeling alone or detached from others).

WHEN DOES PGD OCCUR?

It can happen when someone close to the bereaved person has died at least 12 months earlier for adults or at least 6 months earlier for children and adolescents.

WHY IS PGD IMPORTANT NOW?

"The circumstances in which we are living, with more than 660,000 deaths due to COVID, may make prolonged grief disorder more prevalent. Grief in these circumstances is normal, but not at certain levels and not most of the day, nearly every day for months. Help is available."

- American Psychiatric Association President, Vivian B. Pender, M.D.

Box 1. Proposed DSM Criteria for Prolonged Grief Disorder [a]

A. The death, at least 12 months ago, of a person who was close to the bereaved (for children and adolescents, at least 6 months ago).

B. Since the death, there has been a grief response characterized by one or both of the following, to a clinically significant degree, including nearly every day or more often for at least the last month:

1. intense yearning/longing for the deceased person
2. preoccupation with thoughts or memories of the deceased person (in children and adolescents, preoccupation may focus on the circumstances of the death)

C. As a result of the death, at least 3 of the following 8 symptoms have been experienced to a clinically significant degree since the death, including nearly every day or more often for at least the last month:

1. Identity disruption (e.g., feeling as though part of oneself has died)
2. Marked sense of disbelief about the death
3. Avoidance of reminders that the person is dead (in children and adolescents, may be characterized by efforts to avoid reminders)
4. Intense emotional pain (e.g., anger, bitterness, sorrow) related to the death
5. Difficulty with reintegration into life after the death (e.g., problems engaging with friends, pursuing interests, planning for the future)
6. Emotional numbness (i.e., absence or marked reduction in the intensity of emotion, feeling stunned) as a result of the death
7. Feeling that life is meaningless as a result of the death
8. Intense loneliness (i.e., feeling alone or detached from others) as a result of the death

D. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

E. The duration and severity of the bereavement reaction clearly exceeds expected social, cultural, or religious norms for the individual's culture and context.

F. The symptoms are not better explained by major depressive disorder, posttraumatic stress disorder, or another mental disorder, or attributable to the physiological effects of a substance (e.g., medication, alcohol) or another medical condition.

PGD DSM Criteria

1. Death of close other 12 months ago
2. Nearly every day in last month to clinically significant degree: yearning; preoccupation
3. 3/8: ID disruption; disbelief, avoidance; emotional pain/anger; difficulty reintegrating into life; emotional numbness; meaninglessness, loneliness
4. Impairment

Course of Psychological Responses over Time

PSYCHOLOGICAL RESPONSES TO LOSS OVER TIME

Kubler-Ross' 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

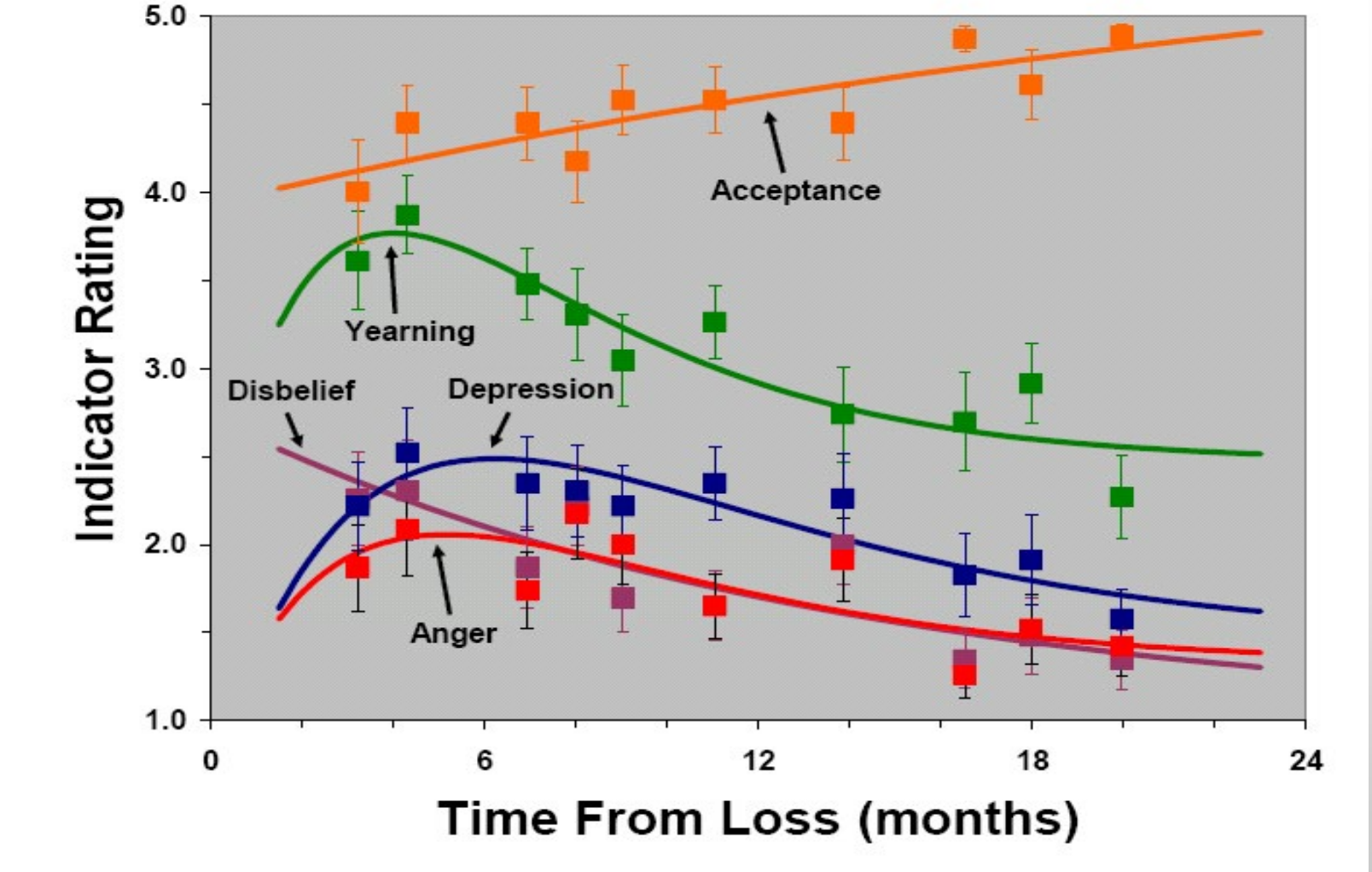
Yale Bereavement Study Tested Stage Theory of Grief

(Maciejewski et al. JAMA 2007)

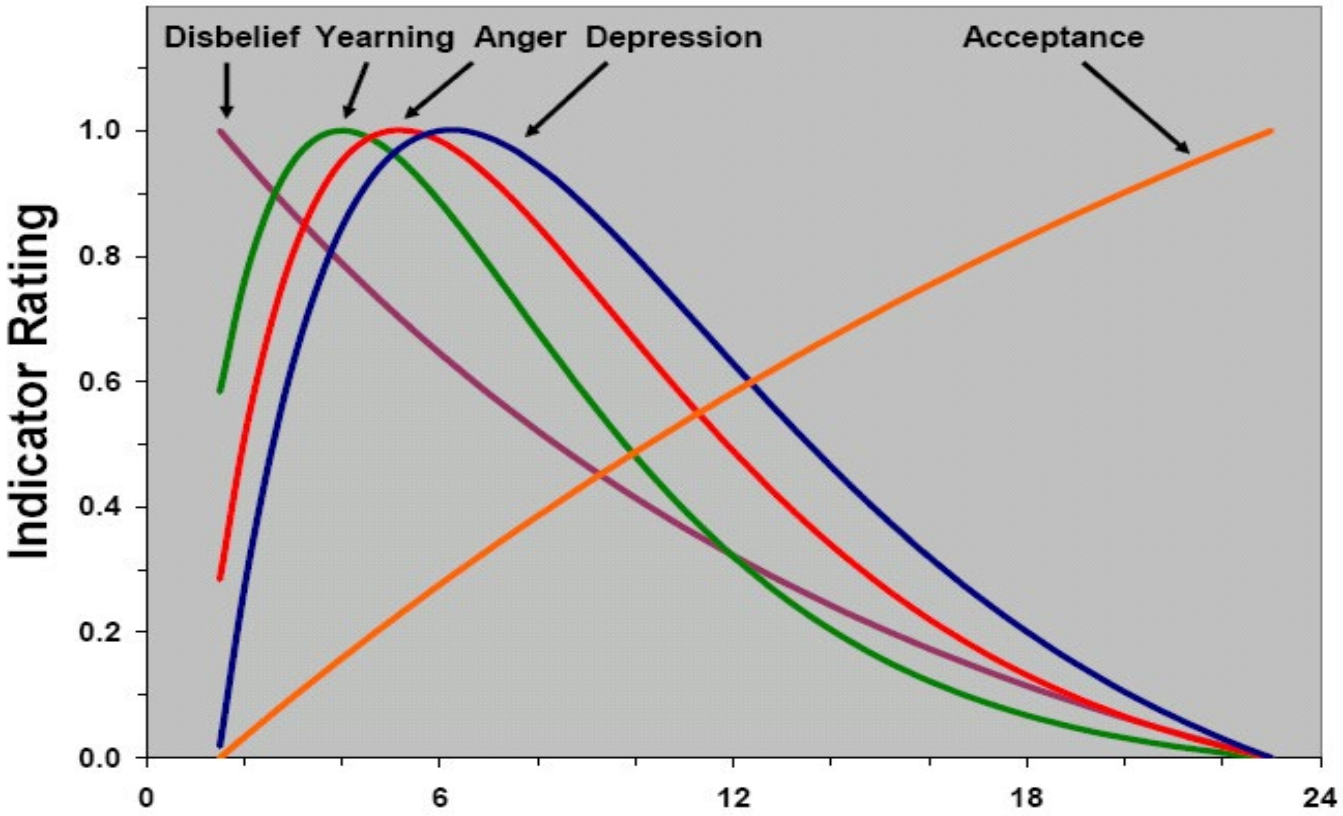
FOR **PROTOTYPICAL BEREAVEMENT** -- LATE-LIFE WIDOWHOOD AFTER NATURAL DEATH …

- MOST BEREAVED PEOPLE ACCEPT DEATH, EVEN INITIALLY
- ACCEPTANCE INCREASES WITH TIME FROM LOSS
- ON SCALE WHERE:

1= < 1/MO; 2= MONTHLY; 3= WEEKLY; *4=DAILY; 5= > 1X/DAY*



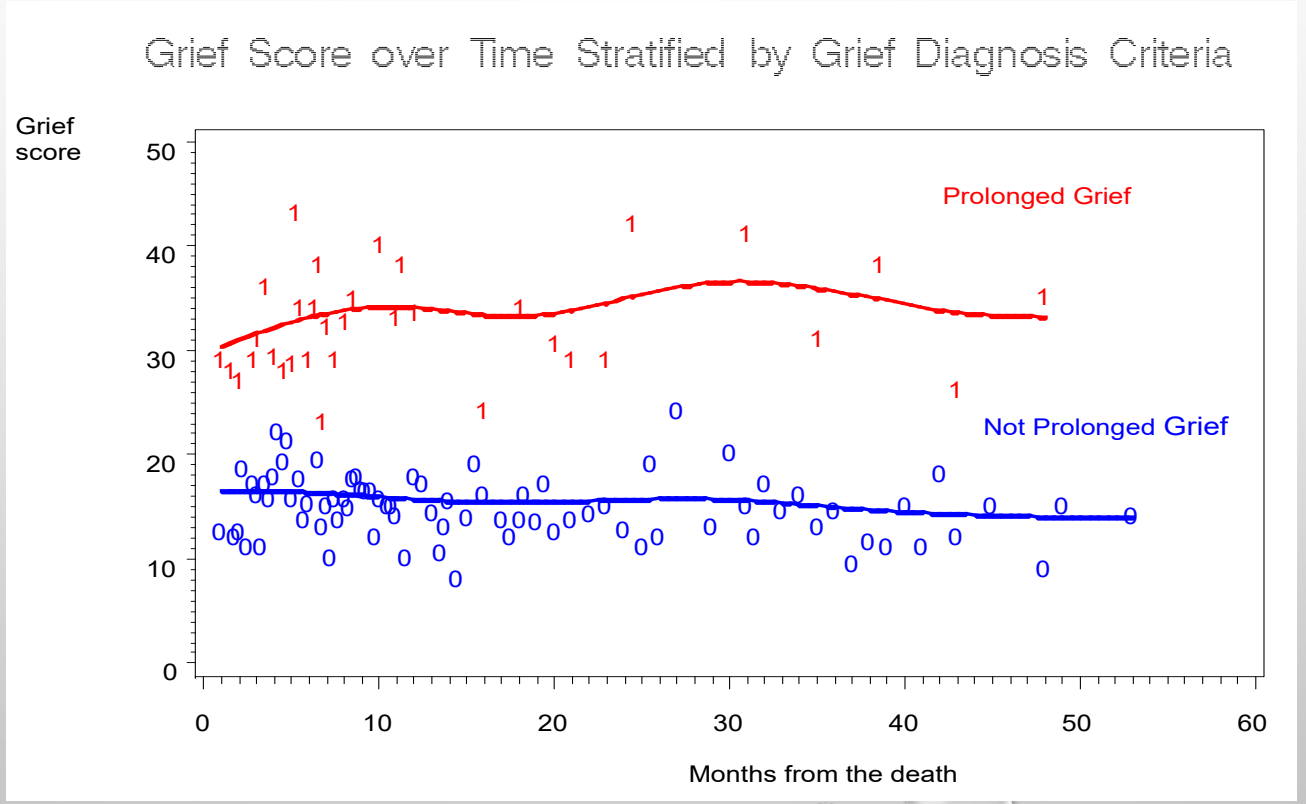
Maciejewski, Zhang, Block, Prigerson JAMA 2007



Maciejewski, Zhang, Block, Prigerson JAMA 2007

BUT THAT'S NORMAL/TYPICAL GRIEF RESOLUTION

SOME BEREAVED ARE STUCK IN AN INTENSE, DISABLING STATE OF GRIEF



RISK FACTORS FOR MENTAL DISORDERS

- CAREGIVERS
- BEREAVED SURVIVORS

"CONTAGION"

Mutuality and Specificity of Mental Disorders Between Patients and Informal Caregivers

Caregiver / Patient

	MDD OR (95% CI)	*P*-value	**PTSD** OR (95% CI)	*P*-value	**GAD** OR **(95% CI)**	*P*-value	**PD** OR (95% CI)	*P*-value	Psych Dx OR (95% CI)	*P*-value
MDD (*N* = 6 3.57%)	ns	ns	ns	ns	ns	ns	ns	ns		
PTSD (*N* = 7 4.17%)	ns	ns	98.16 (2.45–14389.97) [d]	0.0173	17.82 (1.45–227.36)	0.024	9.98 (1.56–65.02)	0.0169		
GAD (*N* = 8 4.76%)	ns	ns	ns	ns	ns	ns	ns	ns		
PD (*N* = 11 6.55%)	ns	ns	ns	ns	**24.73** (4.49–148.04) [d]	**0.0004**	ns	ns		
Psych Dx (*N* = 22 13.10%)									**7.91** (3.02–21.11)	**<0.0001**

Bambauer et al. JSPPE 2006

TABLE 4. ASSOCIATIONS WITH CAREGIVER ANXIETY

	Univariate analyses		*Multivariate analyses*	
Items from SCARED[a]	p *value*	*Odds ratio (CI)*	p *value*	*Odds ratio (CI)*
Confused/delirious				
Experience severe pain/discomfort				
Unable to eat or swallow/Choking				
Vomiting				
Dehydration				
Insomnia				
Falling, passing out, collapsing				
Feeling the patient had had enough				
Thought the patient was dead				
Caregiver burden[b]				

[a]Stressful Caregiver Adult Responses Experience of Dying; [b]as measured by the Caregiver Burden Scale.

Associations between caregiver-perceived delirium in patients with cancer and generalized anxiety in their caregivers. Buss MK[1], Vanderwerker LC, Inouye SK, Zhang B, Block SD, Prigerson HG. J Palliat Med. 2007 Oct;10(5):1083-92.

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Items from SCARED[a]	p *value*	*Odds ratio (CI)*	p *value*	*Odds ratio (CI)*
Confused/delirious	0.004	12.12 (2.26–65.18)	0.04	9.99 (1.07–93.30)
Experience severe pain/discomfort	0.17	3.24 (0.61–17.13)	0.70	1.47 (0.21–10.62)
Unable to eat or swallow/Choking	0.19	2.78 (0.60–12.92)	0.97	1.03 (0.14–7.50)
Vomiting	0.04	5.28 (1.11–25.06)	0.10	6.85 (0.70–67.20)
Dehydration	0.66	1.62 (0.19–14.22)	0.14	0.10 (0.005–2.14)
Insomnia	0.05	5.28 (1.00–27.99)	0.13	4.73 (0.63–35.37)
Falling, passing out, collapsing	0.19	4.43 (0.47–41.91)	0.62	0.44 (0.02–11.77)
Feeling the patient had had enough	0.02	6.67 (1.42–31.24)	0.74	1.43 (0.18–11.25)
Thought the patient was dead	0.28	3.39 (0.37–31.21)	0.48	0.33 (0.02–6.87)
Caregiver burden[b]	0.006	1.13 (1.04, 1.23)	0.14	1.09 (0.97–1.22)

[a]Stressful Caregiver Adult Responses Experience of Dying; [b]as measured by the Caregiver Burden Scale.

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Patient's Place of Death & Bereaved Caregiver's Mental Health Outcomes

Bereaved Caregivers' Mental Health Outcomes	n	N	Patients' Place of Death*											
			Intensive Care Unit			Hospital			Home Without Hospice			Home With Hospice		
			AOR	95% CI	P‡	AOR	95% CI	P‡	AOR	95% CI	P‡	AOR	95% CI	P‡
PTSD	10	238	**5.00**	1.26 to 19.91	.02	0.16	0.009 to 2.94	.22	0.35	0.02 to 7.19	.49	–	Ref	–
GAD	4	236	5.35	0.69 to 41.51	.11	0.47	0.03 to 8.31		0.69	0.03 to 15.68	.81	–	Ref	–
PD	9	238	0.60	0.04 to 9.27	.71	0.95	0.18 to 4.96	.95	0.39	0.02 to 6.75	.52	–	Ref	–
MDD	17	239	3.49	0.86 to 14.22	.08	1.89	0.63 to 5.69	.26	1.34	0.21 to 8.55	.92	–	Ref	–
PGD	15	142	5.24	0.62 to 44.36	.13	**8.83**	1.51 to 51.77	.02	1.98	0.07 to 60.11	.69	–	Ref	–

- **Hospital deaths heighten risk for PGD**
- **ICU deaths heighten risk for PTSD**

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Motivation behind our EMPOWER intervention

- Critical illness can put both patients and caregivers at risk for psychological distress

- Psychological burden may be especially great for surrogate decision-makers (e.g., family caregivers) of incapacitated dying patients in the ICU; further exacerbated by COVID-19 social distancing restrictions

- Need to help these family caregivers in coping with this extremely psychologically distressing situation

EMPOWER: Enhancing & Mobilizing the POtential for Wellness & Emotional Resilience

- An intervention to empower surrogates with tools, psychoeducation, and experiential exercises
- Six ultra-brief (~15- to 20-minute) modules (total time: ~1.5 – 2 hours) **administered flexibly** to accommodate interruptions and crises during the patient's ICU stay
- May be delivered in a single session or 2-3 briefer sessions, with 2 booster calls
- Incorporates cognitive-behavioral, acceptance-based, and grief therapy techniques to assist with coping

The EMPOWER Intervention

In ICU/ Telehealth	Delivered in single or multiple sessions	Module 1	Nurturance, Understanding, and Joining
		Module 2	Breathing Retraining, Grounding Exercises, and Mindfulness Meditation
		Module 3	Psychoeducation about Trauma, Grief, and the Cognitive-Behavioral Model
		Module 4	Increasing Acceptance and Sense of Permission to Experience Challenging Emotions
		Module 5	Connecting with the Patient's Voice
		Module 6	Using the EMPOWER Toolbox and Coping Rehearsal
Phone/ Telehealth	2 weeks post-Module 6	Booster Call 1	Check-in and review of psychoeducation and coping skills
Phone/ Telehealth	4 weeks post-Module 6	Booster Call 2	Check-in and review of psychoeducation and coping skills

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EMPOWERing Surrogates to Cope by Reducing Experiential Avoidance

EMPOWER

- Acknowledge potentially traumatic situation
- Engage in mindfulness, breathing, & grounding exercises
- Provide psychoeducation re: peritraumatic stress, anticipatory grief, & experiential avoidance
- Review cognitive-behavioral and acceptance-based strategies to build distress tolerance
- Invoke patient's values and perspective to aid in surrogate decision-making using role-play

EMPOWER = Enhancing & Mobilizing the POtential for Wellness & Emotional Resilience
PTSD = Posttraumatic Stress Disorder
PGD = Prolonged Grief Disorder

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

Note. Between-groups Cohen's d comparing EMPOWER to EUC.

Participant Exit Interview Feedback

"It wasn't something I was really looking forward to or looking to when I didn't think it was going to be helpful for me at the time because there's so much on my mind. But after being placed in the room and having to actually talk about it when I barely had time - - to eat or - - let alone think about oh I should get to therapy. It wasn't something I was actually thinking of. But at the end of the day it really--I don't want it to feel overdramatic in saying, like, it saved my sanity. But it really did, you know, really did give me a support that I didn't really think I needed until everything--until I actually did it and then I realized what a weight off my shoulders it felt like to be able to talk about it… So, you know, I sat down and asked questions about things right in the hospital - - kind of if I had to I just go out and take care of something with my mother. So it was very helpful. I can't express how helpful it was." -EMPOWER1

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Conclusions

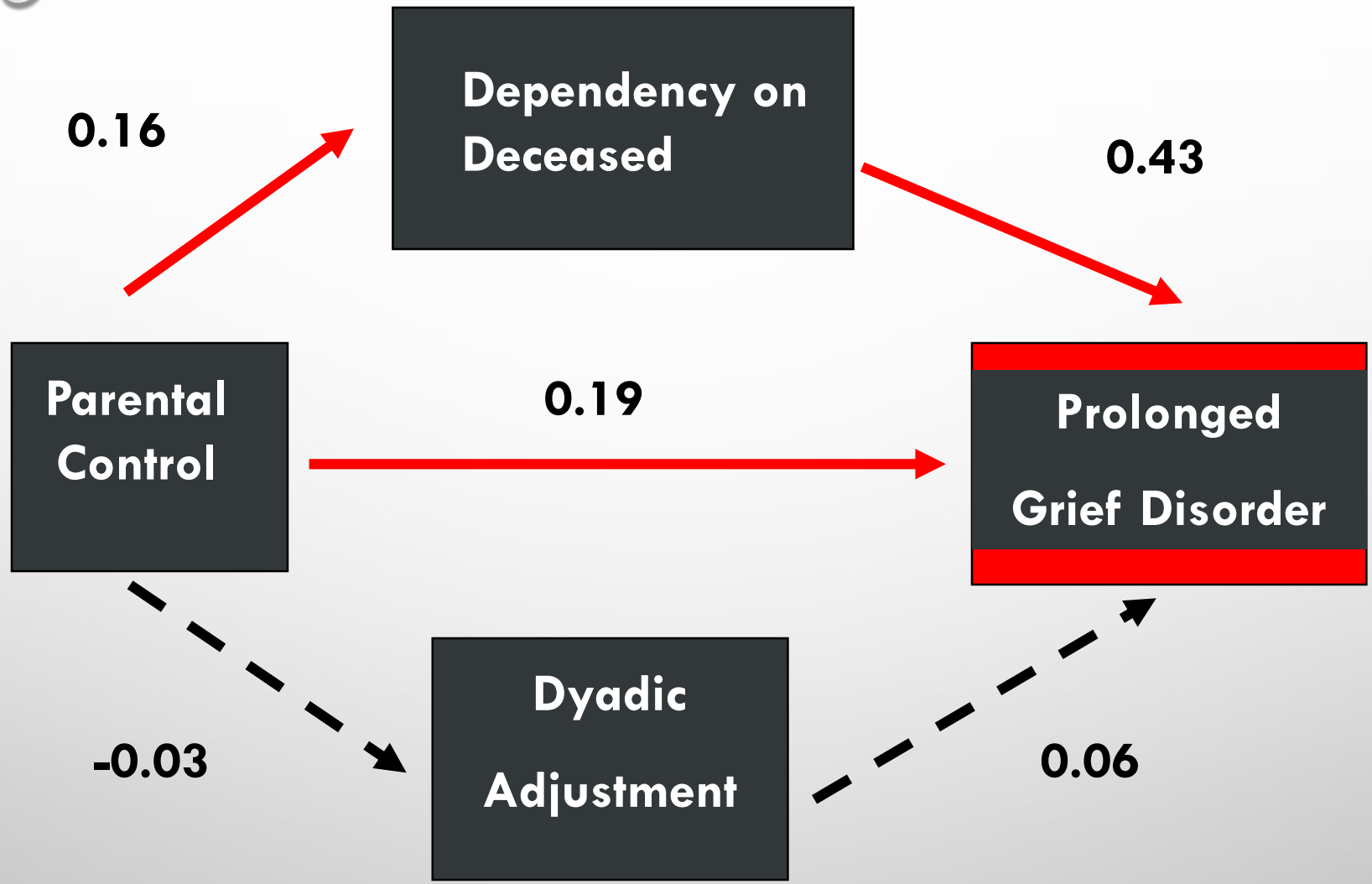
1. DYING PATIENTS AND THEIR PERSONAL CAREGIVERS EXPERIENCE SIGNIFICANT SYMPTOMS OF **ANXIETY, DEPRESSION, GRIEF, & PERITRAUMATIC STRESS**
2. THESE SYMPTOMS MOSTLY RESOLVE OVER TIME AS PEOPLE **COME TO ACCEPT** OR BECOME RESIGNED TO THE LOSS, BUT CAN PREDICT ENDURING DISTRESS AND DISABILITY (**PTSD, PGD**)
3. **ICU/HOSPITAL STAYS** AND DEATHS RESULT IN MORE **PSYCHIATRIC MORBIDITY** FOR PATIENTS AND FAMILY **CAREGIVERS**
4. **EMPOWER** IS A PSYCHOSOCIAL INTERVENTION TO REDUCE PSYCH DISTRESS, IMPROVE EOL DECISION-MAKING AND CARE, AND RESULT IN BETTER CAREGIVER ADJUSTMENT

THANK YOU FOR YOUR ATTENTION

Disclosure Statement:

In compliance with the ACCME Standards for Commercial Support of CME, neither I nor any planners of this activity have any relevant financial relationships to disclose in relation to this presentation.

Risks for Mental Disorders Among Bereaved Caregivers



Johnson JG, Zhang B, Greer JA, Prigerson HG. JNMD 2007

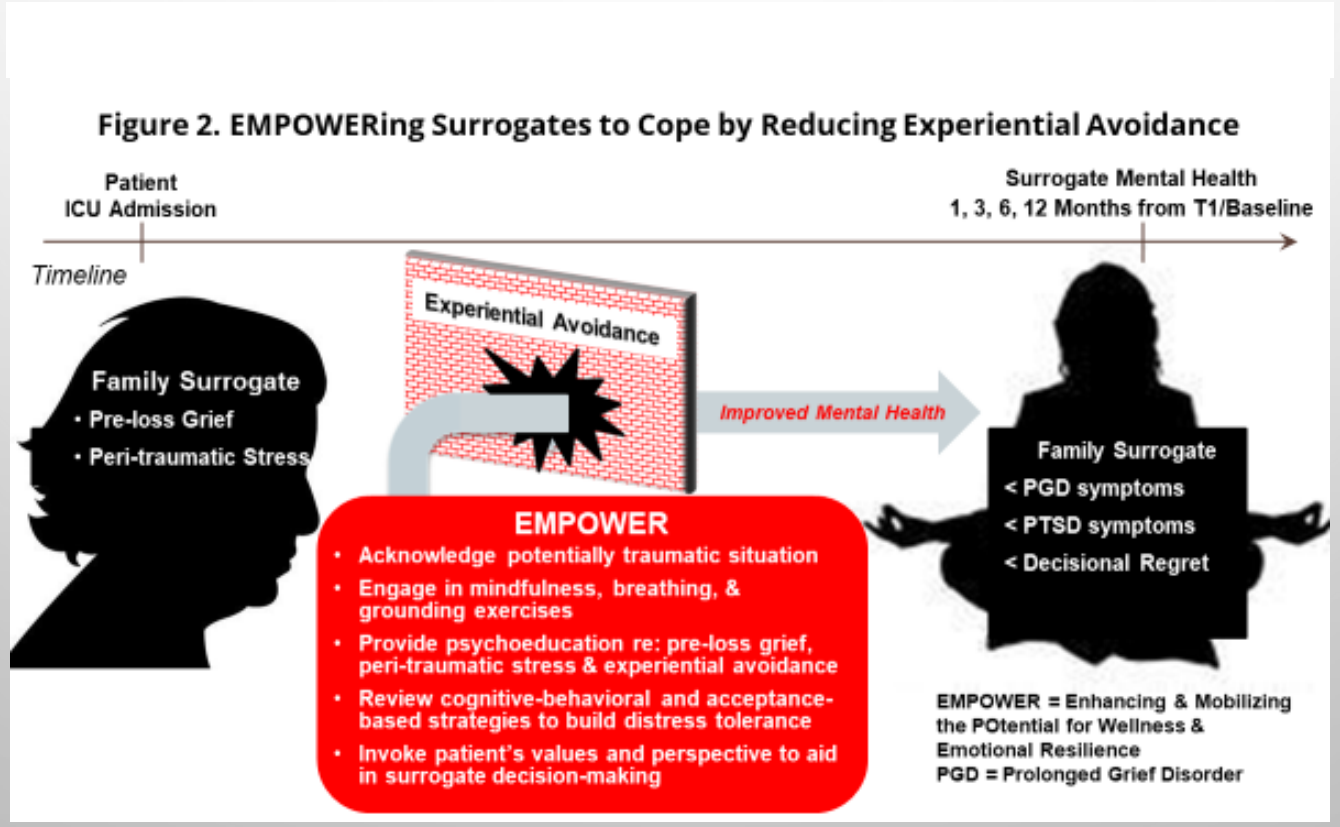
CAREGIVER'S RELATIONSHIP TO DYING PATIENT AND RISK FOR PGD VS. MDD

Van Doorn et al. 1998

MARITAL QUALITY	PGD		MDD	
	R	P	R	P
• 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, EMOTIONAL SUPPORT	**.69**	.0001	.23	NS
• OVERALL QUALITY OF MARRIAGE	.39	.01	.03	NS

Reduced Experiential Avoidance May Mediate Changes

Reductions in posttraumatic stress symptoms were associated with reductions in experiential avoidance from baseline to 3 months post-intervention ($p < .01$), suggesting the mediating role of experiential avoidance



PERITRAUMATIC STRESS IN FAMILY CAREGIVERS OF CRITICALLY ILL PATIENTS

RISK FACTORS

- CAREGIVERS OF **YOUNGER PATIENTS** REPORTED GREATER **PERITRAUMATIC DISTRESS** (P=0.007) AND **DISSOCIATION** (P=0.002)

- **LONGER ICU STAYS** WERE ASSOCIATED WITH GREATER SYMPTOMS. CAREGIVERS WHO REPORTED GREATER OVERALL **SYMPTOM BURDEN FOR THE PATIENT** HAD HIGHER **PERITRAUMATIC DISTRESS** (P<0.001) AND **DISSOCIATION** (P=0.03)

- **DISSOCIATION** SYMPTOMS WERE HIGHER AMONG CAREGIVERS OF **PATIENTS** WHO COULD **NOT COMMUNICATE** (P=0.01); **PERITRAUMATIC DISTRESS** SHOWED A SIMILAR PATTERN (P=0.10)

Derry et al. (2020)

Grief, Depression, & Anxiety Form Distinct Symptom Clusters in Bereaved Family Members

Symptoms	Grief	Depression	Anxiety
depressed mood	.10	*.71*	-.31
blue	.07	*.66*	-.16
anxious	-.18	-.22	*.52*
nervous	-.13	-.22	*.88*
yearn	*.62*	.21	.02
intrusive thoughts	*.68*	.26	-.10
ID symptoms	*.77*	-.03	.02
drawn->reminders	*.71*	.15	-.12
feel presence	*.82*	-.02	-.08

Prigerson et al. *Am J Psychiatry* 1995