Prolonged Grief Disorder (PGD): Diagnosis, Risks, Resources & Interventions

11th Annual Great Lakes Conference
Lake Geneva, Wisconsin, May 4-5th, 2023

Holly G. Prigerson, PhD

Irving Sherwood Wright Professor of Geriatrics
Professor of Sociology in Medicine
Weill Cornell Medicine
Co-Director, Center for Research on End-of-Life Care
Cornell University

Presentation Overview

I. How to diagnose Prolonged Grief Disorder (PGD)
   a) diagnostic criteria
   b) differential diagnosis re: typical grief, bereavement-related depression, and PTSD
   c) misconceptions about PGD diagnosis

II. A micro-sociological theory of social voids as risk factors for PGD

III. An application of the theory & review of bereavement interventions & resources

I.a. What are the DSM-5-TR criteria for PGD?

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?

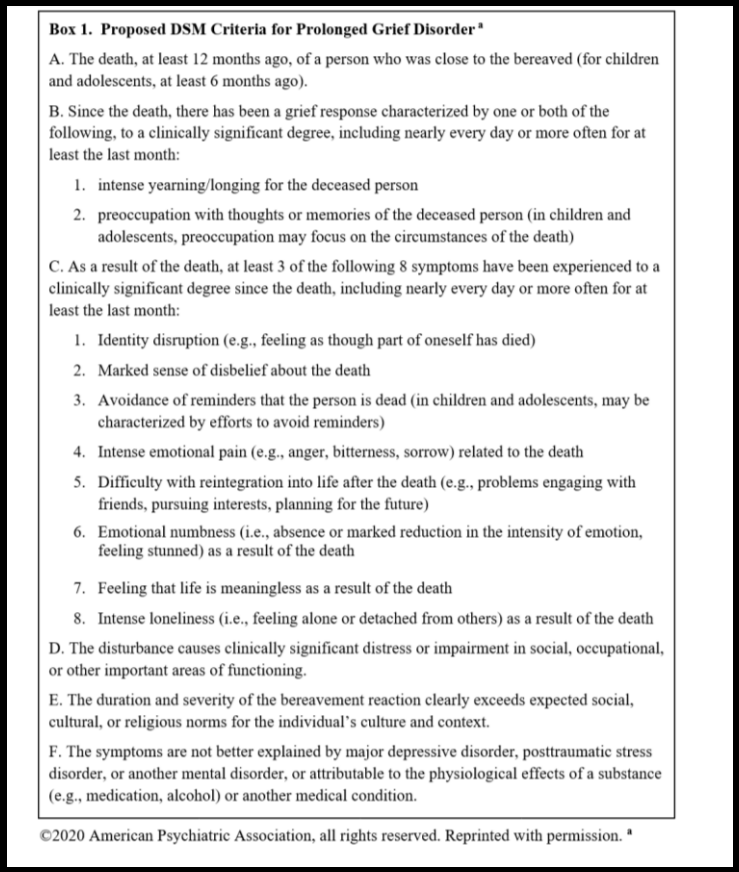
"The circumstances in which we are living, with more than 660,000 deaths due to COVID, may make prolonged grief disorder more prevalent. Grief in these circumstances is normal, but not at certain levels and not most of the day, nearly every day for months. Help is available."

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

What is Prolonged Grief Disorder?

- Chronic, intense, distressing reaction to loss distinct from bereavement-related depression and anxiety --
  - it is, essentially, intense, crippling **heartache**: which *Oxford Dictionary defines as*… "emotional anguish or grief, typically caused by the loss or absence of someone loved"
- **Unlike typical 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 <4% following normal circumstances of loss

PGD DSM Criteria



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.

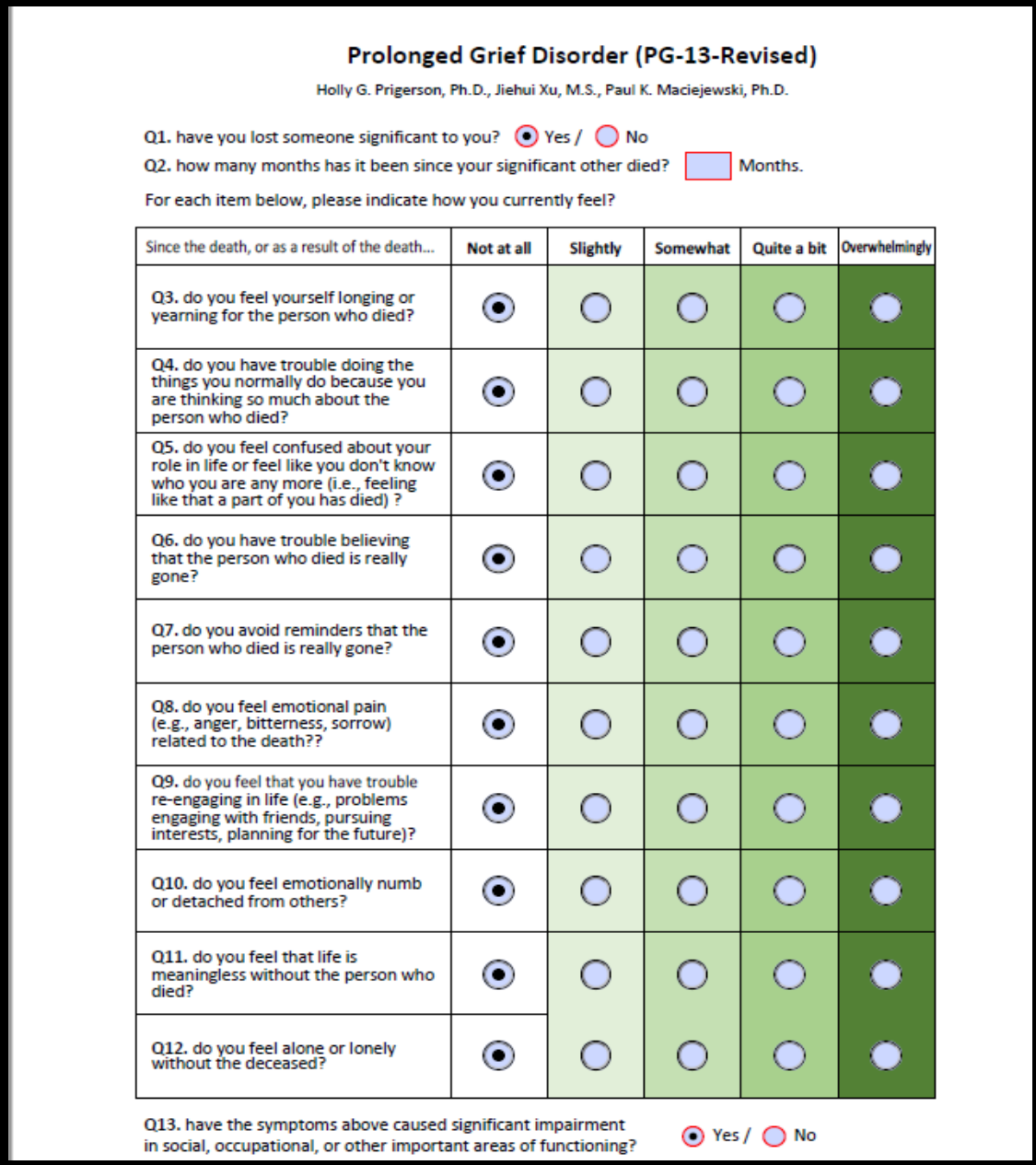
F. The symptoms are not better explained by major depressive disorder, posttraumatic stress disorder, or another mental disorder, or attributable to the physiological effects of a substance (e.g., medication, alcohol) or another medical condition.

1. Death of close other 12 months ago

1. 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



Prolonged Grief Disorder (PG-13-Revised)

Holly G. Prigerson, Ph.D., Jiehui Xu, M.S., Paul K. Maciejewski, Ph.D.

Q1. have you lost someone significant to you? (•) Yes / ( ) No

Q2. how many months has it been since your significant other died? [ ] Months.

For each item below, please indicate how you currently feel?

Since the death, or as a result of the death...	Not at all	Slightly	Somewhat	Quite a bit	Overwhelmingly
Q3. do you feel yourself longing or yearning for the person who died?	( )	( )	( )	( )	( )
Q4. do you have trouble doing the things you normally do because you are thinking so much about the person who died?	( )	( )	( )	( )	( )
Q5. do you feel confused about your role in life or feel like you don't know who you are any more (i.e., feeling like that a part of you has died) ?	( )	( )	( )	( )	( )
Q6. do you have trouble believing that the person who died is really gone?	( )	( )	( )	( )	( )
Q7. do you avoid reminders that the person who died is really gone?	( )	( )	( )	( )	( )
Q8. do you feel emotional pain (e.g., anger, bitterness, sorrow) related to the death??	( )	( )	( )	( )	( )
Q9. do you feel that you have trouble re-engaging in life (e.g., problems engaging with friends, pursuing interests, planning for the future)?	( )	( )	( )	( )	( )
Q10. do you feel emotionally numb or detached from others?	( )	( )	( )	( )	( )
Q11. do you feel that life is meaningless without the person who died?	( )	( )	( )	( )	( )
Q12. do you feel alone or lonely without the deceased?	( )	( )	( )	( )	( )

Q13. have the symptoms above caused significant impairment in social, occupational, or other important areas of functioning? (•) Yes / ( ) No

Prigerson HG, et al. Validation of the new DSM-5-TR criteria for prolonged grief disorder and the PG-13-Revised (PG-13-R) scale. World Psychiatry. 2021 Feb;20(1):96-106.

Available from Cornell Center for Research on End-of-Life Care website

Center for Research on End-of-Life Care (cornell.edu)

Structured Clinical Interview for PGD (SCIP)

as well as in a forthcoming

APPI Handbook on Grief and PGD

I. b. Differential diagnosis re: typical grief, bereavement-related depression & PTSD

How to diagnose PGD

Distinguishing PGD from…

- Typical grief

&

- MDD

… secondary to bereavement

How to distinguish PGD from *typical grief*

Typical grief looks something like this…

How to distinguish PGD from *MDD secondary to bereavement*

MDD following bereavement looks something like this…

Table 1. Differences between Prolonged Grief Disorder (PGD) and Major Depressive Disorder (MDD) Secondary to Bereavement

PGD	MDD
• Yearning, longing, pining for deceased	• Yearning not characteristic of MDD
• Sadness in response to thinking about the loss	• Pervasive low mood, sadness
• Bittersweet emotions evoked by memories of the deceased	• Inability to feel joy or happiness in response to memories of the deceased
• Pangs of grief (waves of emotion related to missing the deceased)	• Pangs of grief not characteristic of MDD
• It's "personal" -- person-specific, response to close other	• Not person-specific, pervasive low mood and not triggered exclusively by an interpersonal loss
• It's "social" – an experience of social, interpersonal deprivation and precipitating need for reconfiguration of social network	• It's "psychological" – an internal, emotional experience
• Chronic, persistent state	• Episodic, comes and goes
• Evokes identity disturbance (questioning sense of self, who one is and where one fits in, roles, feeling un-whole)	• Evokes feelings of low self-esteem, worth, but not necessarily identity disturbance or role confusion
• Disbelief, lack of acceptance of the death	• Expect bad outcomes, expectations confirmed rather than shattered

Table 2. Differences between Prolonged Grief Disorder (PGD) and Posttraumatic Stress Disorder (PTSD) Secondary to Bereavement

PGD	PTSD
• Yearning, longing, pining for deceased	• Yearning not characteristic of PTSD
• Preoccupation with thoughts of deceased, evoking sense of missing	• Intrusive thoughts about the death, typically focused on the circumstances of the death
• Avoidance of reminders that the deceased is truly gone and permanently unavailable	• Avoidance of reminders of the death
• Bittersweet emotions evoked by memories of the deceased	• Memories of death evoke fear and horror
• Pangs of grief (waves of emotion related to missing the deceased)	• No pangs of grief • Unbidden images of the death that haunt rather than console
• It's "personal" -- person-specific, response to close other (i.e., the "who", not the "how" of the death/loss)	• Not person-specific, rather event-specific, linked to a psychologically traumatic experience that evokes extreme fear, helplessness, or horror; (i.e., the "how", not the "who" of the death/loss)
• It's "social" – an experience of social, interpersonal deprivation	• It's "psychological" – an intrapersonal emotional reaction to a traumatic exposure
• Hyper-focus, preoccupation with thoughts of deceased; deliberate, reminiscing that evokes feelings of safety and security	• Hypervigilance; hyper-focus on potential dangers; unwanted thoughts and fears
• Searching for the deceased, and/or imagining seeing him or her	• No searching but keen focus on possible threats to safety
• Disengagement and loss of interest in other people	• Hyper-alert to scan environment for danger; other people perceived as potential threat
• Social support system affected	• Social support system not necessarily affected

How Long Should It Take to Grieve? Psychiatry Has Come Up With an Answer.

Misconceptions about PGD

1. ***PGD diminishes family support, stigmatizes mourners, medicalizes grief to push unwanted treatment***

- > 90% bereaved individuals reported their family/friends would be ***more*** understanding if diagnosed w/ PGD – diagnoses are largely comforting
- 96% "**relieved** that they had a **recognizable problem**"
- 96% would be "**relieved** to know they **weren't going crazy**"
- 100% meeting PGD criteria would be **interested in treatment**

Johnson et al. 2009

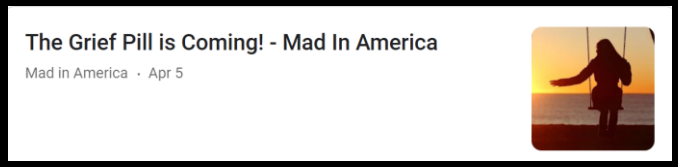
How Long Should It Take to Grieve? Psychiatry Has Come Up With an Answer.

Misconceptions about PGD

2. *PGD criteria too easy to meet, thus pathologizes normal /typical grief*

- dx criteria are *hard* to meet, only 38 of 2498 (4%) German bereaved sample met criteria -- only 1% of the full sample
- dx criteria have 1.4% false positive rate
- dx criteria require severe distress & impairment -- pathology is "baked in" to PGD dx
- dx criteria predictive of suicidality & MDD, bodily pain, worse general health, vitality, social & role function, heart attacks

Rosner et al. *JAD,* 2021; Maciejewski et al. *World Psychiatry,* 2016



Misconceptions about PGD

3. Evidence for PGD is thin

- >600 peer-reviewed articles; 10 systematic reviews in past 5 Years
- Ample evidence of validity & reliability (e.g., Prigerson et al. *World Psychiatry* 2021 analysis of 3 international, independent bereaved samples)
- Innumerable cross-cultural validation studies, including the International Workgroup on Grief in Children – UK, Ukraine, Turkey, Iran

4. No such thing as stages of grief; time heals all wounds…

- **Average response *does* reveal clear patterns**
- **Not** ALL wounds heal. Some leave scars, some mourners get stuck…

Psychological responses to loss over time

Kubler-Ross' Stage Theory of ("Normal") Grief:

Disbelief, Anger, Bargaining, Depression, Acceptance (DABDA)

Disbelief
"deer in headlights"
shocked/stunned

Anger

Bargaining

Depression

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

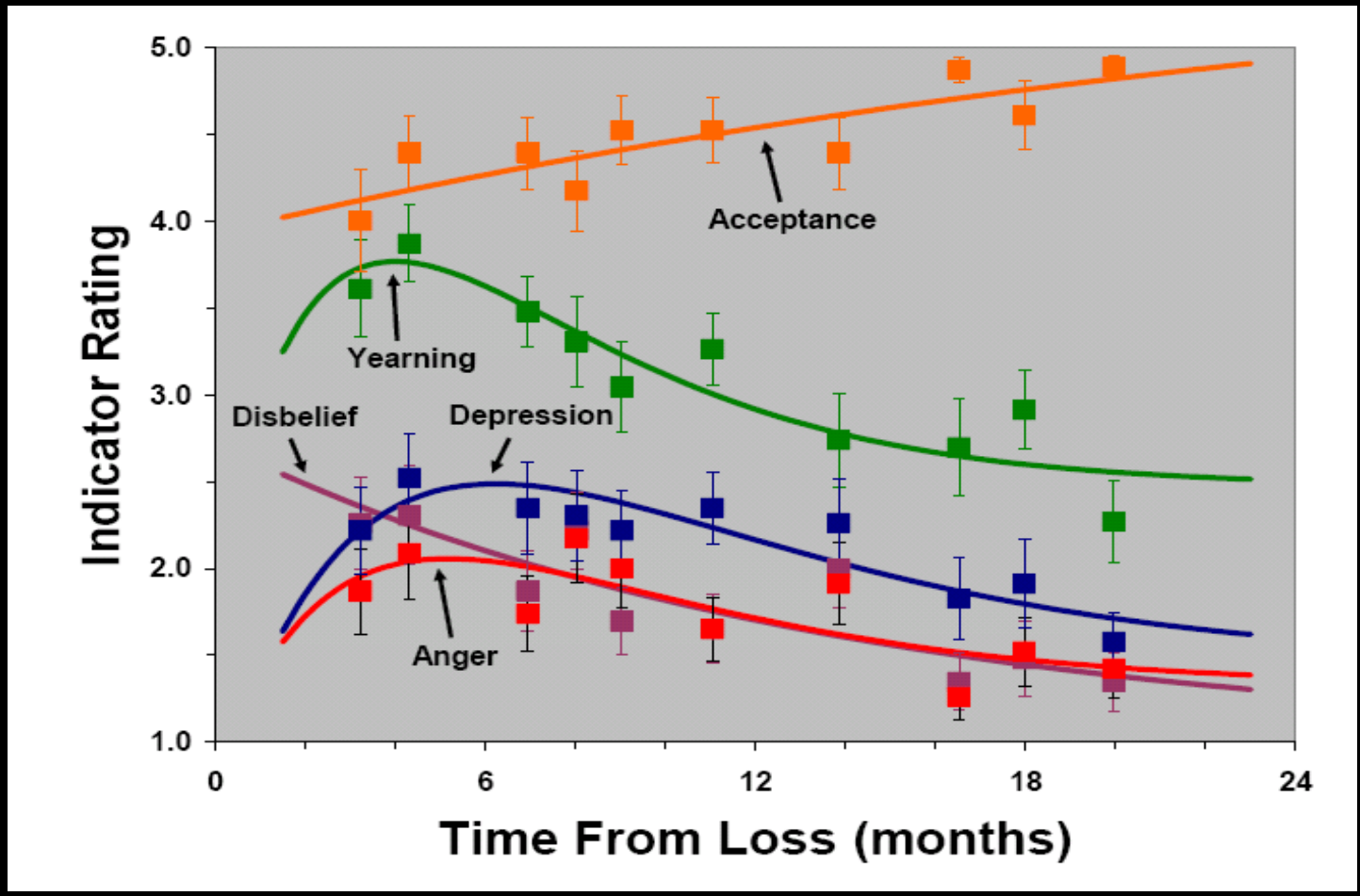
Yale Bereavement Study Tested Stage Theory of Grief

(Maciejewski et al. JAMA 2007)

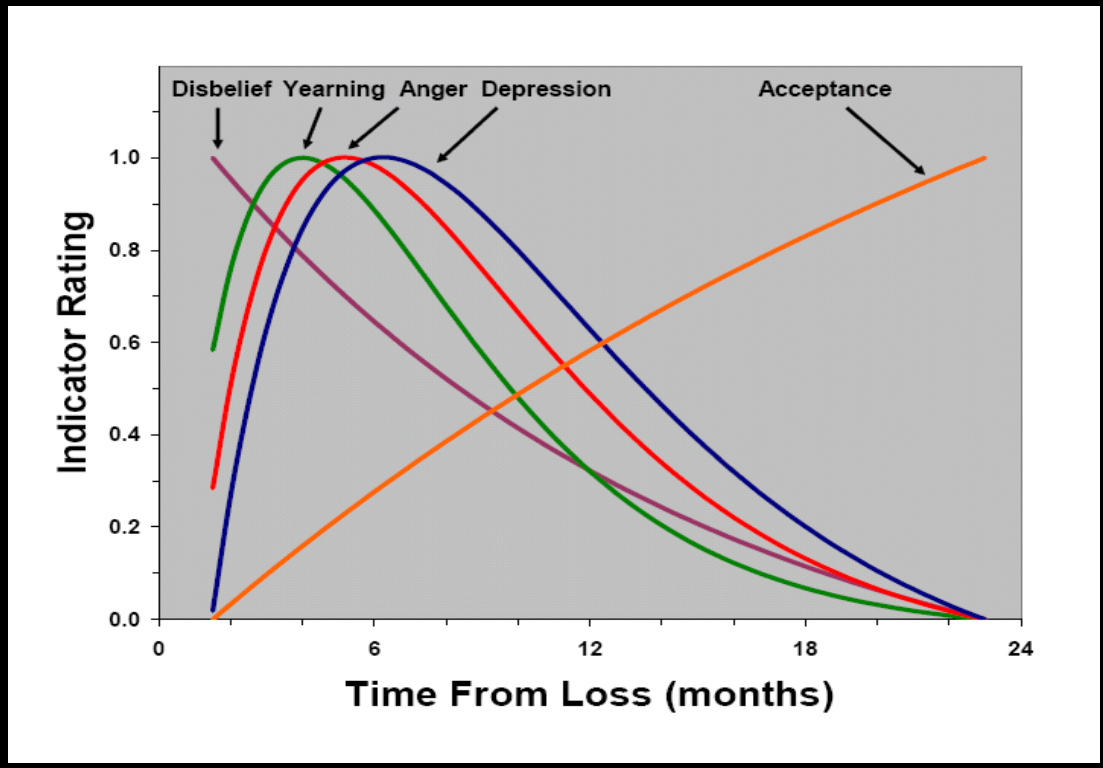
For **prototypical bereavement** -- late-life widowhood after natural death …

- 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*



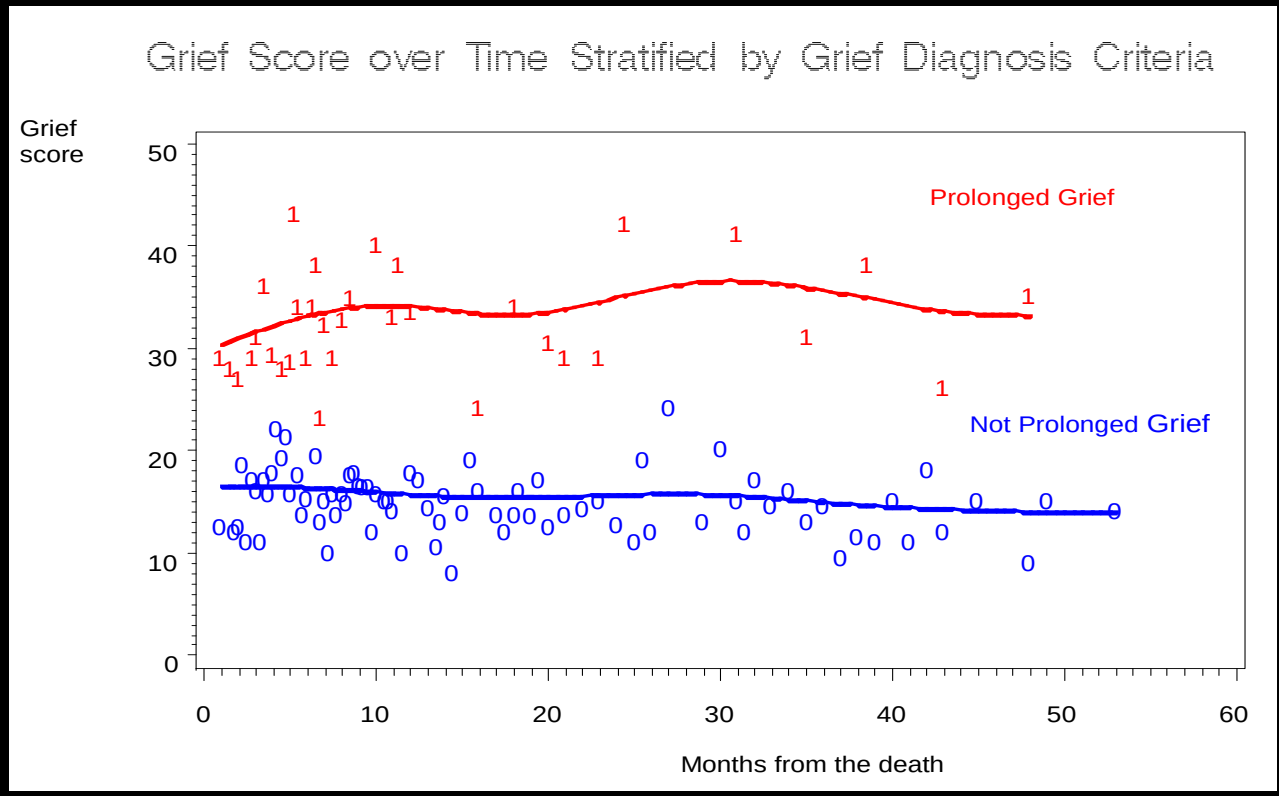
Maciejewski, Zhang, Block, Prigerson *JAMA* 2007



Maciejewski, Zhang, Block, Prigerson *JAMA* 2007

But that's typical grief resolution.

A subset of extreme cases of bereaved individuals become stuck…



II. A micro-sociological theory of adjustment to loss

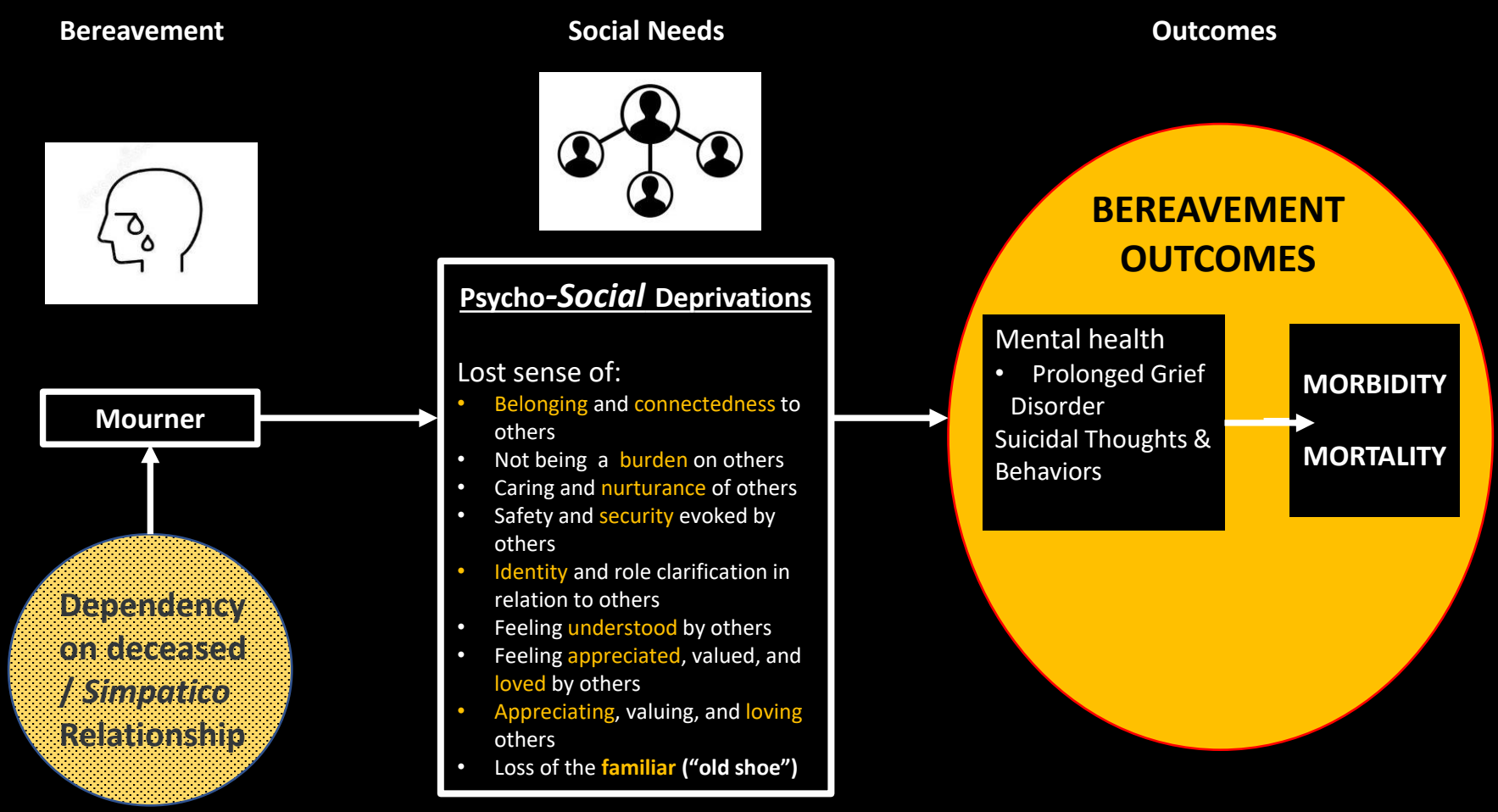
Aristotle famously wrote:

"nature abhors a vacuum"

The phrase expresses the idea that unfilled spaces go against the laws of nature and that every space needs to be filled with something.

Does the same hold true for the "**social space**" created by an interpersonal loss? It would appear healthy, natural, and adaptive to fill this social space adaptively to address social voids.

Figure 1. **A Conceptual Model Relating the Satisfaction of Psychosocial Needs to Bereavement Adjustment**

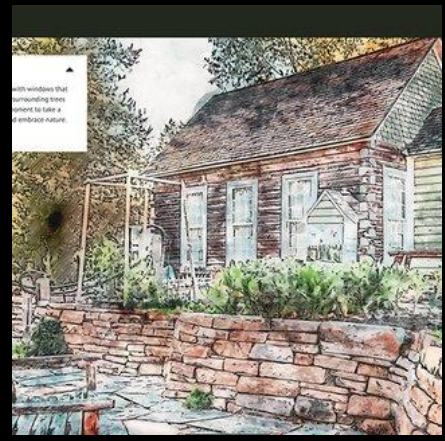


Maciejewski PK, Falzarano FB, She WJ, Lichtenthal WG, Prigerson HG. A micro-sociological theory of adjustment to loss. Curr Opin Psychol. 2022 Feb;43:96-101.

Interventions targeting social deprivations identified in the micro-sociological theory of adaptation to loss:

1. Living Memory Home – expressive writing

2. Finding My Way – suite including LMH, Cognitive Reframing, Simpatico



Living Memory Home

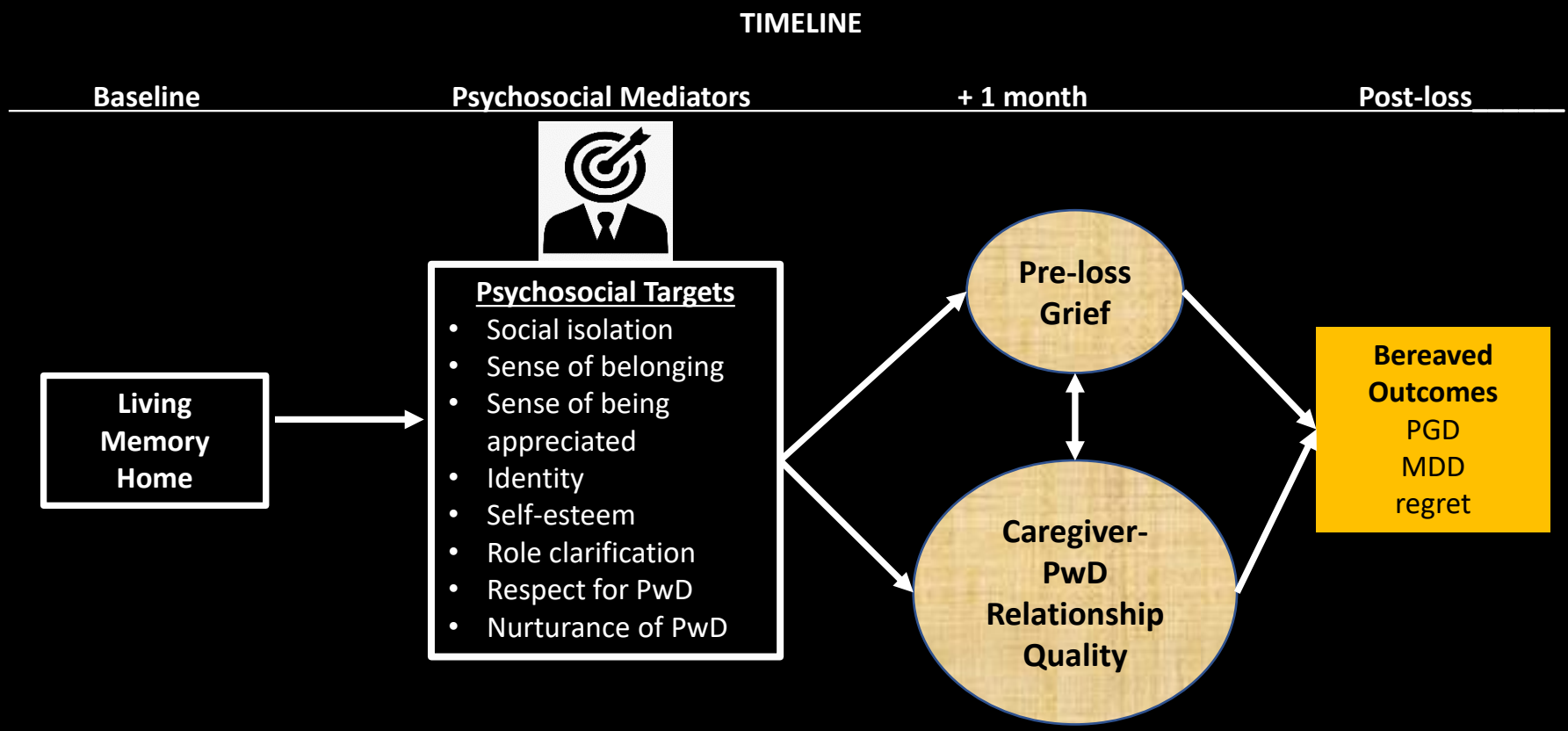
1. Online place to create & store memories of the dying or deceased person

2. Online journal with prompts to promote positive sharing (e.g., “what I always admired about you was…”; “I always wanted to tell you…”)

3. Bereaved caregivers a place to maintain continuing bonds; text monitored by machine learning algorithm to detect those with significant suicidal risk

4. Dementia “care pairs” an activity to document sources of pride & joy before too late – addresses pre-loss grief in dementia

Figure 1. Conceptual Model of Psychosocial Deprivations Targeted by the Living Memory Home to Reduce Grief & Improve Relationship Quality in Dementia "Care Pairs"



Finding My Way

1. Online tool that includes:

   a) LMH journaling

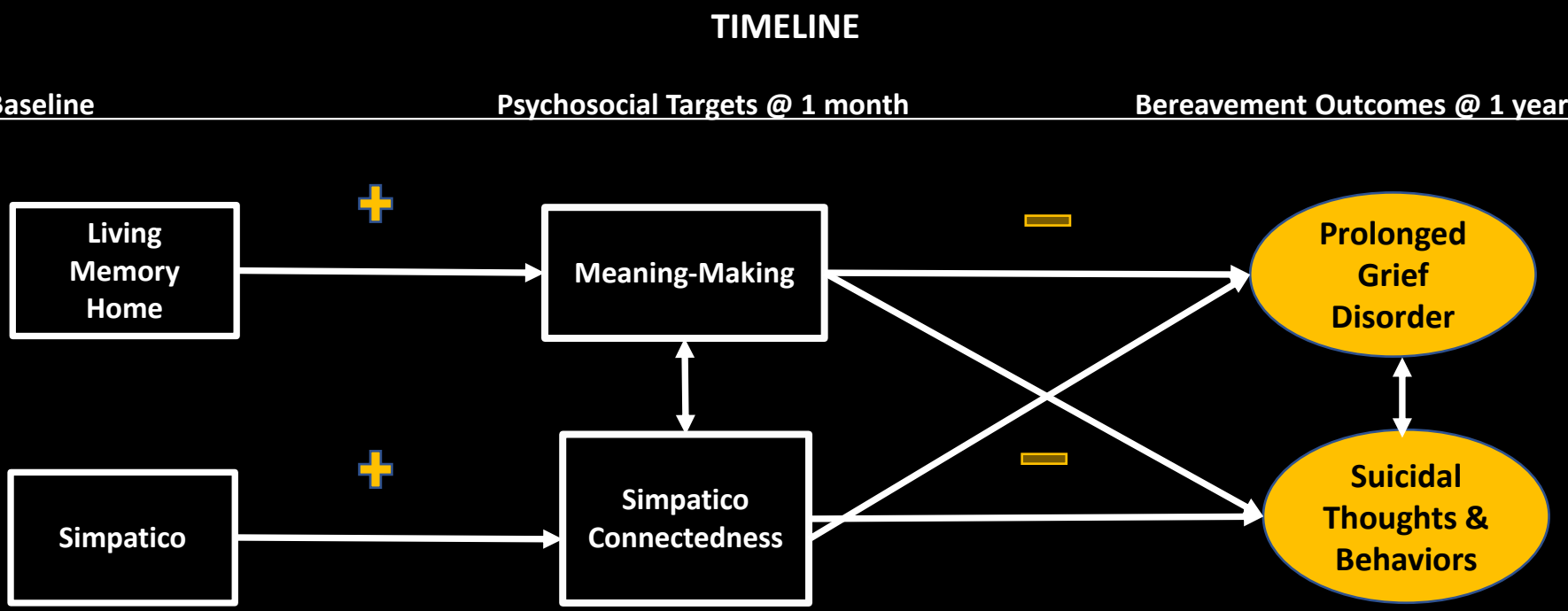
   b) Cognitive reframing of negative bereavement cognitions exercises

   c) Social mapping

   d) Social skills training

   e) **Simpatico** "connecting with others" match-making algorithm connecting "like" (cause of death, kinship, interests) bereaved others

Figure 1. **Conceptual model of how *Finding My Way* components relate to targets expected to prevent onset of *Prolonged Grief Disorder* (PGD) & *Suicidal Thoughts & Behaviors* (STBs) in bereavement**



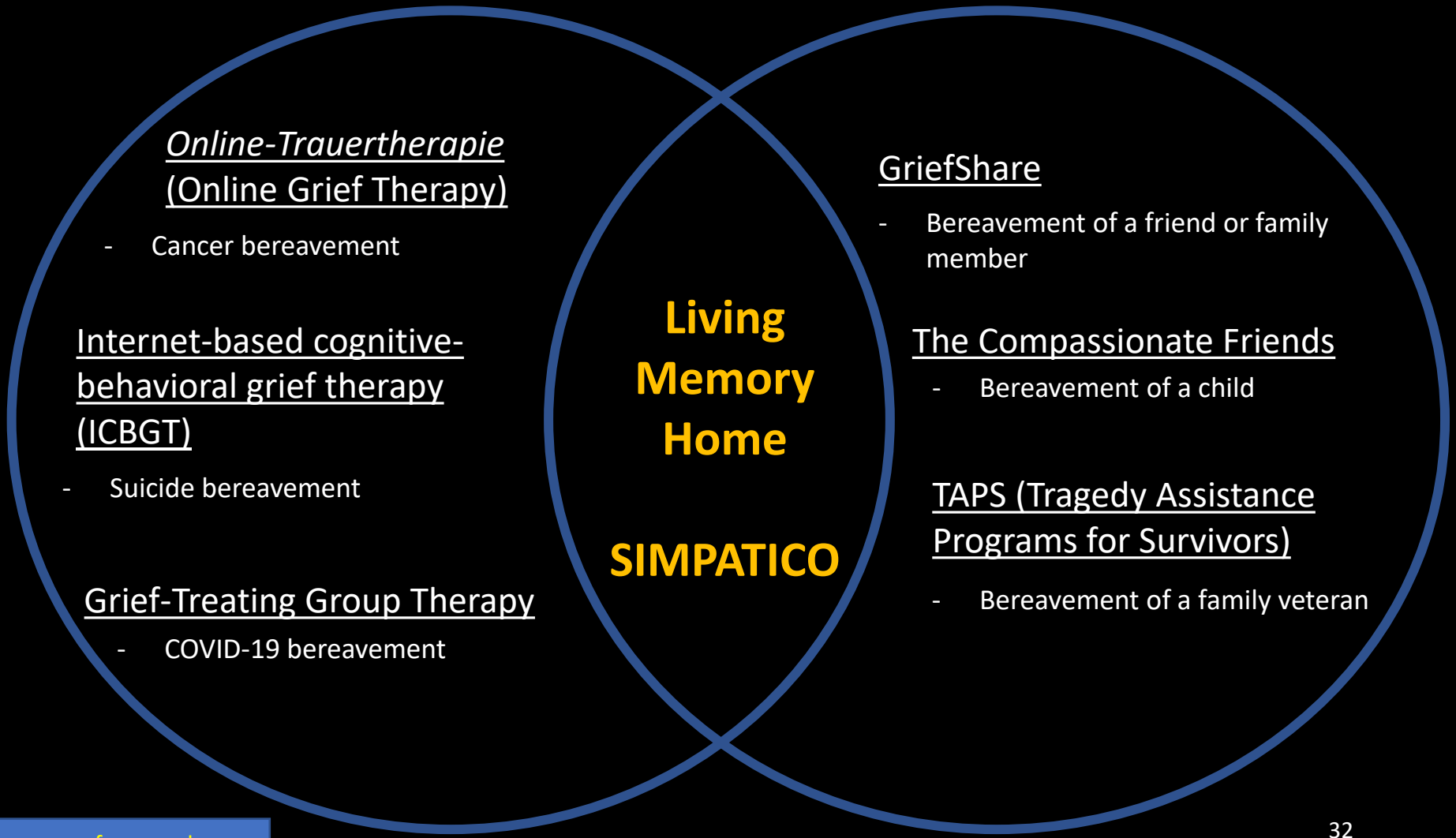
III. Treatment implications: Overview of…

a) Online Interventions / Support

b) Psychotherapies

c) Medications

Online Interventions / Support



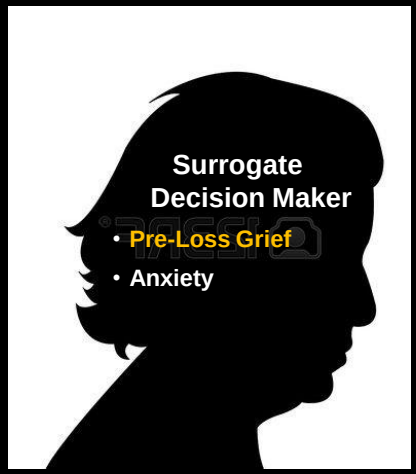
see references here

III. a) 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

EMPOWERing Surrogates to Cope by Reducing Experiential Avoidance

Patient
ICU Admission



Caregiver Mental Health
1 & 3 Months from T1/Baseline

EMPOWER

- Acknowledges potentially traumatic situation
- Engages in mindfulness, breathing, & grounding exercises
- Provide psychoeducation re: peri-traumatic stress, anticipatory grief, & experiential avoidance
- Reviews CBT & ACT strategies to build distress tolerance
- Invokes patient's values for role-play

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

- An intervention to empower surrogates with tools, psychoeducation, & experiential exercises
- 6 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 meaning-centered 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

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

Medications Treatments for PGD

Medications	PROS	CONS
Antidepressants [SSRI, TCA]	Helpful in **reducing symptoms** of anxiety, depression, and sleep disturbances associated with PGD	- Mixed/lacking evidence that supports treatment specific for PGD - Some medications are not recommended for long-term use - **Not addressing intense longing for the person who has died**
Antipsychotics [risperidone, olanzapine]	Helpful in **reducing intrusive thoughts**, hallucinations, or delusions	
Benzodiazepines [lorazepam, diazepam, clonazepam]	Helpful in **promoting relaxation** and reducing anxiety-related symptoms for grief	

The Naltrexone Trial

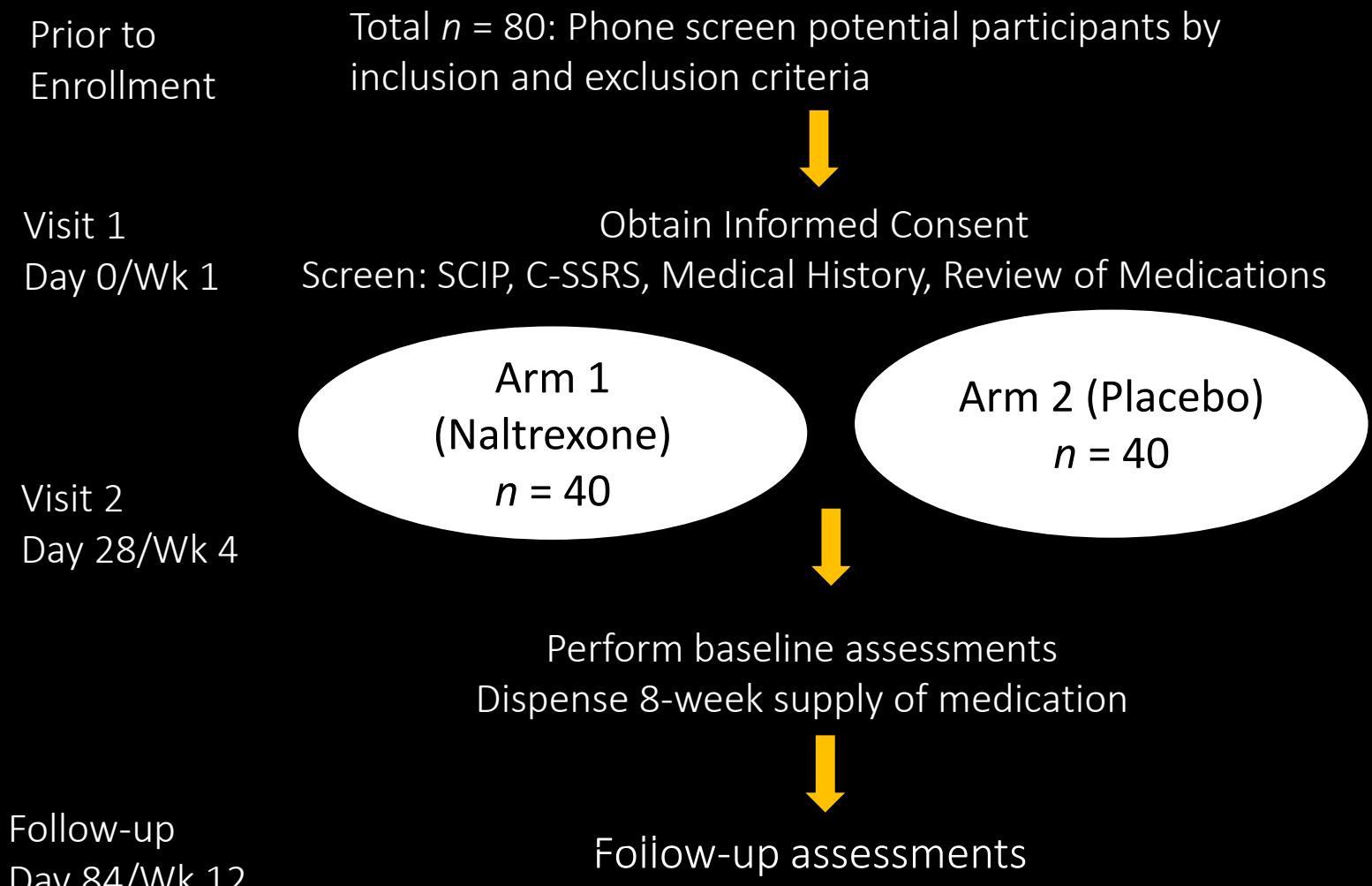
our approach

see references here

III. b) Motivation for our Naltrexone Trial

- Established therapies for bereavement-related depression – TCAs & IPT – *not work for PGD sxs*
- PGD is characterized by ***yearning*** for deceased – pangs of grief reminding mourners of their heartache (don't have pangs/yearning/craving for others -- not missing them)
- Nucleus accumbens activation linked to ***yearning*** specific to deceased person
- Naltrexone blunts ***yearning*** for rewarding stimulus, which should free mourner from grips of grief & promote openness to others

The Naltrexone Trial



Individualized Psychotherapies

Complicated Grief Therapy (CGT) **Shear**

- Aimed at facilitating adaptation to loss and addressing intense grief that interferes with functioning
- 16 sessions
- Those diagnosed with PGD responded greater to CGT 88.2% than those without CGT 60.9% ($p<0.001$)

Metacognitive Therapy (MCGT) **Breen**

- Designed to help individuals process their ”thoughts about thoughts” and regulate unhelpful, intrusive thoughts and rumination.
- 6, 2-hour sessions
- Reduction in PGD symptoms (Cohen's d=1.7), depression (d=1.3), anxiety (d=0.8), stress (d=1.0), rumination (d=0.9) and increased quality of life (d=0.6) (n=10)

Present-Centered Therapy (PCT) **Kersting**

- Develop patients’ understanding of their symptoms and encourage mastery in problem solving
- Significant reductions in PGD symptoms determined by the PG-13 before and after treatment.
- Self-reported PGD symptoms (ICG) revealed a significant large effect from pre- to post-treatment with d = 1.0 (n= 20).

Meaning-Centered Therapy
Breitbart/Lichtenthal

- 1-on-1 CBT-existential intervention that used psychoeducation, experiential exercises, and structured discussion to explore themes related to meaning, identity
- Results showed postintervention longitudinal improvements in **prolonged grief** (d = 1.7), sense of meaning (d = 2.1), depression (d = 0.8), hopelessness (d = 1.0), continuing bonds with their child (d = 1.3), posttraumatic growth (ds = 0.3-1.3), positive affect (d = 1.0.), and various health-related quality of life domains (d = 0.5-0.7).

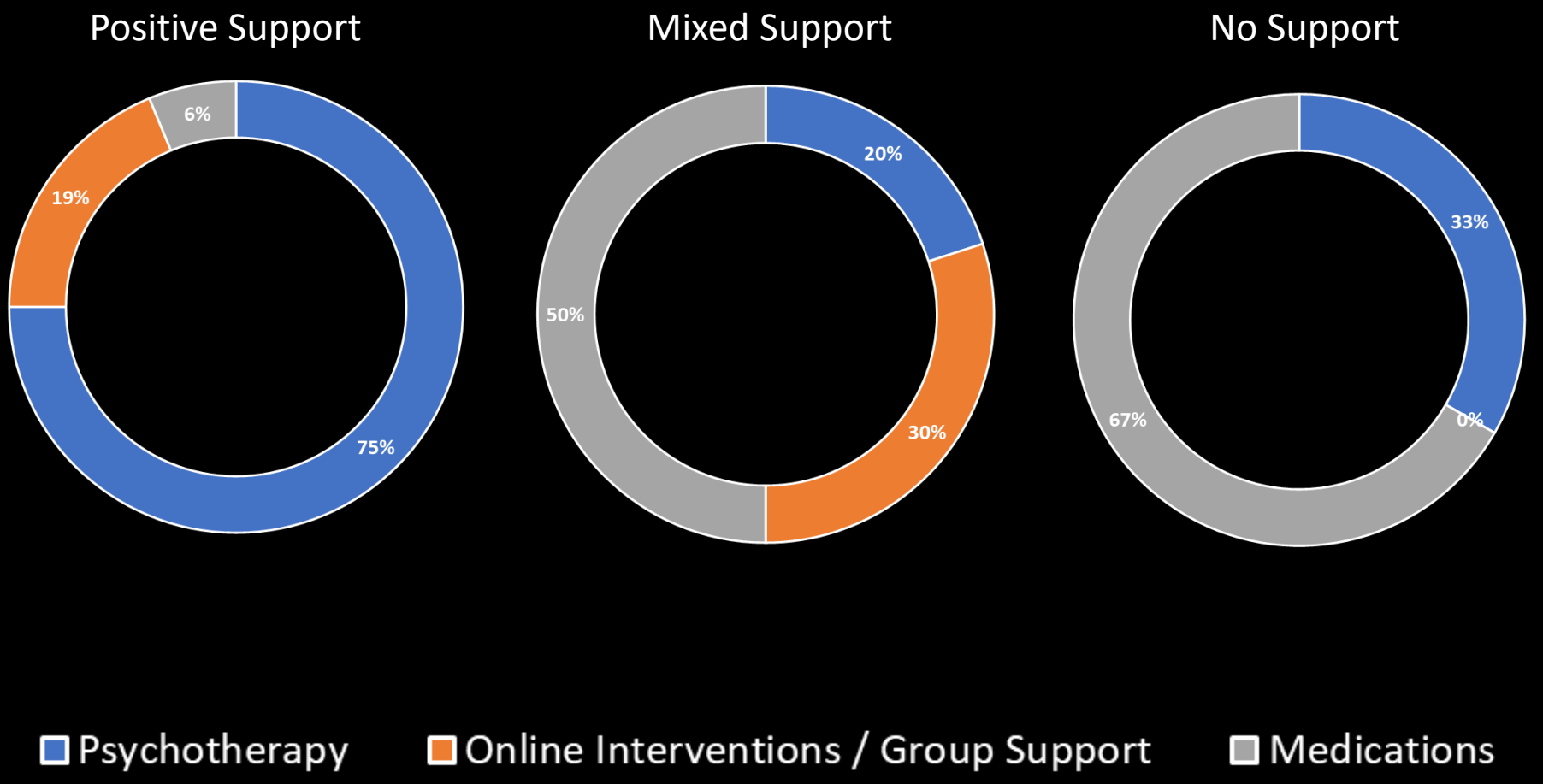
Psychotherapies for PGD

see references here

Type of Psychotherapy	Goals for Treatment	Support for PGD
Cognitive Behavorial Therapy (CBT)	Implements cognitive restructuring to help confront and process grief.	When utilized with exposure techniques, CBT can greatly reduce PGD, depression, negative appraisals, and functional impairment.
Metacognitive Therapy (MCGT)	Designed to help individuals process their ”thoughts about thoughts” and regulate unhelpful, intrusive thoughts and rumination.	MCGT showed promising evidence that as a therapy, it can improve an individual’s symptoms of anxiety, stress, and rumination.
Present-Centered Therapy (PCT)	Structured under the framework for PTSD treatment, with main goal being to develop patients’ understanding of their symptoms and encourage mastery in problem-solving.	Though novel and still developing, PCT showed significant reductions in PGD symptoms determined by the PG-13 before and after treatment.
Meaning-Centered Grief Therapy (MCGT)	Focuses on helping individuals find and reconstruct meaning and purpose in their lives after experiencing a significant loss.	MCT was associated with significant reductions in PGD symptoms (d=1.7) among parents who lost a child to cancer.
EMPOWER	Incorporates what we know from cognitive-behavioral, acceptance-based, and meaning-centered therapy techniques to assist with coping with loss.	Compared to a supportive conversation, EMPOWER is an intervention to provided surrogates at risk of PGD with tools, psychoeducation, & experiential exercises and reduced PGD symptoms.

see references here

Supportive Treatments and Therapies



Grief Support Resources

- **Grief and Sympathy – a Site for Coping with Grief and Expressing Sympathy**
- **Good Grief – Compassion. Support. Community**
- **The Compassionate Friends – Supporting Family After a Child Dies**
- **Open to Hope – Giving a Voice to Grief and Recovery**
- **TAPS (Tragedy Assistance Programs for Survivors) - Caring for the Families of America's Fallen Heroes**

In conclusion, we have …

I. Discussed how to diagnose PGD
   a) shared diagnostic criteria
   b) how to make a differential diagnosis
   c) refuted misconceptions

II. Presented our micro-sociological theory of adjustment to loss
   a) provided some examples of applications in online interventions

III. Discussed PGD interventions & their efficacy
   a) psychotherapies
   b) medications
   c) resources

Conclusion

THANK YOU FOR YOUR ATTENTION.

I wish to acknowledge the contributions of Frankie Osso, Paul Maciejewski, Wendy Lichtenthal, Francesca Falzarano, and Maddie Rogers in support of this work and thank Hillary Winoker for her assistance with preparation of these slides.

Please contact me at:
hgp2001@med.cornell.edu
with your feedback.

THE END