Background Context for This Presentation

This live webinar was given by Dr. Christopher Layne on March 25, 2020, while he was Program Director of Education in Evidence-Based Practice at the UCLA/Duke University National Center for Child Traumatic Stress, and a Research Psychologist in the UCLA Department of Psychiatry and Biobehavioral Sciences.

- Prior to the inclusion of prolonged grief disorder (PGD) in DSM-5-TR (American Psychiatric Association--APA, 2022), a provisional disorder (Persistent Complex Bereavement Disorder-PCBD) was included in the Appendix of DSM-5 (APA, 2013) to invite further study and clinical evaluation. Dr. Layne and his colleagues had been actively involved in developing an assessment tool—the PCBD Checklist, validating the measure, developing grief-focused interventions, and evaluating outcomes of grief-focused interventions in bereaved youth.
- The summer prior (June 2019), Dr. Layne had represented a team of child grief researchers and clinicians in presenting to the APA a set of developmental recommendations for a Prolonged Grief Disorder in DSM-5-TR (Layne, Kaplow, Oosterhoff, & Hill, 2019). These recommendations drew heavily from the team's work in developing and validating the PCBD Checklist and its utility for assessing outcomes of grief-focused interventions. (See the Team's 2019 report for a transcript of the presentation and supporting references)
- The Team had presented its final developmental recommendations to the APA in a written report submitted one month prior to this webinar (Layne, Oosterhoff, Pynoos, & Kaplow, February 2020).
- As a next step, the APA was preparing to open a website inviting public commentary in Summer 2020.
- Accordingly, the primary aims of this presentation were to review: (a) proposed criteria for DSM-5-TR Prolonged Grief Disorder, (b) the Team's proposed developmental recommendations, and (c) types of scientific evidence being used to evaluate the merits of including a grief disorder in DSM-5-TR. A fourth primary aim was (d) to prepare, motivate, and mobilize the audience to participate as informed consumers in the upcoming APA public commentary.

A recording of this webinar is available on the NCTSN website ttps://learn.nctsn.org/course/view.php?id=533

Developmental Recommendations and Implications for a Prolonged Grief Disorder (PGD) in DSM-5-TR:

Become an Informed Consumer and Advocate

25 March 2020

Speaker

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UCLA-Duke University National Center for Child Traumatic Stress and
Department of Psychiatry and Biobehavioral Sciences,
University of California, Los Angeles

Reference Citation for this webinar:
Layne, C. M. (2020, March 25). Developmental Recommendations and Implications for a Prolonged Grief Disorder (PGD) in DSM-5-TR: Become an Informed Consumer and Advocate. [Webinar] Los Angeles, CA & Durham, NC: National Center for Child Traumatic Stress. https://learn.nctsn.org/course/view.php?id=533.

Author Disclosures

Christopher Layne is a co-author of:

- Trauma and Grief Component Therapy: A Modular Approach to Treating Traumatized and Bereaved Youth (Saltzman, Layne, Pynoos, Olafson, Kaplow, & Boat; Cambridge University Press, 2017)
- The Persistent Complex Bereavement Disorder Checklist (Layne, Kaplow, & Pynoos, 2014; Behavioral Health Innovations, LLC, www.reactionindex.com).

Dr. Layne is on the Scientific Advisory Board of Behavioral Health Innovations, LLC.

Learning Objectives

1. List the timeline and activities for adopting Prolonged Grief Disorder (PGD) in DSM-5-TR.
2. Describe DSM-5-TR draft criteria for PGD.
3. Discuss our recommended developmental modifications to the draft PGD criteria.
4. Discuss opportunities that a psychiatric disorder can bring to the field of child and adolescent bereavement.
5. Explain how a strength-based approach to understanding grief can raise the standard of bereavement care.
6. Summarize empirical evidence and current events surrounding PGD.

Co-Authors of APA Presentation and Final Report

- **Layne, C. M., Kaplow, J. B., Oosterhoff, B., & Hill, R.** (2019, June 3). Developmental Perspectives on DSM-5-TR Prolonged Grief Disorder Criteria: Proposals for Improvement. Invited presentation at the Workshop on Developing Criteria for a Disorder of Pathological Grieving for DSM 5-TR. Hosted by the American Psychiatric Association, New York City (Paul Applebaum, M.D., Chair).

- **Layne, C. M., Oosterhoff, B., Pynoos, R. S., & Kaplow, J. B.** (4 February 2020). Developmental Analysis of Draft DSM 5-TR Criteria for Prolonged Grief Disorder: Report from the Child and Adolescent Bereavement Subgroup. Report submitted to the Panel on Developing Criteria for a Disorder of Pathological Grieving for DSM 5-TR (P. Applebaum, Chair). American Psychiatric Association.

Information Sources: Published and Unpublished

Our June 2019 initial presentation and February 2020 final report made use of two data sets:

- New York Life Foundation-funded **GIFT (Grief-Informed Foundations of Treatment; Co-PIs: Kaplow and Layne)** practice research network data set (N = 367) as collected from five different sites across the U.S.

- Data (N = 760) from the **SAMHSA-funded Trauma and Grief Center at Texas Children's Hospital/Baylor College of Medicine** (PI: Kaplow).

COVID-19 and Risk for Difficult Grieving

"...Sadly, this pandemic is already associated with tremendous loss of lives worldwide. There are many aspects of COVID-19 that will increase the risk of grief derailers. Availability of effective grief therapy is more important than ever."

--Katherine Shear, M.D.

Letter to Professional Community

23 March 2020

Learning Objective

1

Timeline and Activities for Adopting Prolonged Grief Disorder (PGD) in DSM-5-TR

Timeline for Adding PGD to DSM-5-TR

- APA website: https://bit.ly/dsm-5-proposed-changes
- The APA received a proposal to modify the criteria for Persistent Complex Bereavement Disorder (PCBD)—a provisional disorder listed in DSM 5.0 under Conditions for Further Study--and incorporate the revised disorder into Section 2 thus making it a formal diagnosis.
- The Proposal was extensively reviewed by the APA Internalizing Disorders Review Committee, chaired by Roberto Lewis-Fernandez, MD.
- In **June 2019**, the APA held a workshop and invited three major research groups to present their data on diagnostic validity, reliability, clinical utility. Presenters included:
  - Katherine Shear, MD (Columbia) and Charles Reynolds, MD (Pitt);
  - Holly Prigerson, PhD and Paul Maciejewski, PhD (Cornell);
  - Christopher Layne, PhD and Robert Pynoos, MD (UCLA) presented on behalf of Layne, Kaplow, Oosterhoff, & Hill (2019)
- An expert panel, chaired by David Brent, MD, was convened to review the data, listen to the workshop presentations, probe conclusions, and identify areas of disagreement that required resolution.

Timeline for Adding PGD to DSM-5-TR

- At the end of the June 2019 workshop, the three research groups had reached an agreement on a set of draft criteria for Prolonged Grief Disorder.
- The research groups were given homework assignments asking them to test proposed criteria in their existing data sets to determine:
  1. optimal number of Criterion C symptoms to require, (optimizing specificity/sensitivity),
  2. items that best predicted future symptoms and impairment,
  3. diagnostic reliability, and
  4. discriminant validity.

Timeline for Adding PGD to DSM-5-TR

- In the **Fall of 2019**, the Shear/Reynolds and the Prigerson/Maciejewski groups submitted reports that were reviewed by the expert panel.
- The APA Panel concluded that there was strong/substantial evidence that PGD:
  - met the definition of a mental disorder,
  - manifested evidence of diagnostic validity,
  - possessed good clinical utility,
  - showed good discriminant validity,
  - had good test-retest reliability,
  - cut-off of 3/8 symptoms for Criterion C,
  - duration of 12 months after bereavement before making diagnosis, and
  - text would include notes regarding ways in which presentations might differ in children.

Timeline for Adding PGD to DSM-5-TR

- Panel report was reviewed by the Internalizing Disorders Review Committee, who endorsed the report.
- Proposed PGD criteria set was reviewed and approved by the DSM Steering Committee.
- In Feb 2020, the child/adolescent team submitted their final report.
- **The PGD criteria set is now posted**, awaiting 45-day public comment period (**April 6-May 20, 2020**)
- Comments will be reviewed by Internalizing Disorders Review Committee and the DSM Steering Committee to determine whether changes are required.
- Once the proposal is finalized, it must be approved by:
  - **APA Assembly**, which meets in **November 2020**, and
  - if approved by the APA Assembly, the **APA Board** will consider it in either **December 2020 or March 2021**.
- If approved by the APA Board, PGB criteria become final, will be incorporated into the online version of DSM (which is official/canonical), and any future printed versions of DSM.

Learning Objective

2

DSM-5-TR Draft Criteria for Prolonged Grief Disorder (PGD)

NOTE: These do not contain our developmental recommendations.

DSM-5-TR Draft Criteria for PGD

A. The death of a person close to the bereaved at least 12 months previously.

B. Since the death, there has been a grief response characterized by intense yearning/longing for the deceased person or a preoccupation with thoughts or memories of the deceased person. This response has been present to a clinically significant degree nearly every day for at least the last month.

DSM-5-TR Draft Criteria for PGD

C. As a result of the death, at least 3 of the following symptoms have been experienced to a clinically significant degree, nearly every day, 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
4. Intense emotional pain (e.g., anger, bitterness, sorrow) related to the death
5. Difficulty moving on with life (e.g., problems engaging with friends, pursuing interests, planning for the future)
6. Emotional numbness
7. Feeling that life is meaningless
8. Intense loneliness (i.e., feeling alone or detached from others)

DSM-5-TR Draft Criteria for PGD

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

E. The duration 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 another mental disorder.

Learning Objective

3

Recommended Developmental Modifications to the Draft PGD Criteria

(in bolded blue ink)

These recommendations draw from the GIFT Network and TAG Clinic data sets, our 2019 presentation and 2020 final report, and from: Kaplow, J.B., Layne, C. M., Pynoos, R.S., Cohen, J., & Lieberman, A. (2012). DSM-V diagnostic criteria for bereavement-related disorders in children and adolescents: Developmental considerations. *Psychiatry, 75,* 243-266.

Proposed Modifications: A-B

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

B. Since the death, there has been a grief response **characterized by one or both of the following two symptoms:**

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

   This response has been present to a clinically significant degree nearly every day for at least the last month.

Proposed Modifications: C

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

1. Identity disruption (e.g., feeling as though part of oneself has died). **(Note: Children and adolescents may express this discontinuity as now feeling different from others and often self-conscious as a result, e.g., weird or different as a result of being motherless.)**
2. Marked sense of disbelief about the death. **(Note: Young children may not understand the permanence of death.)**
3. Avoidance of, or efforts to avoid, reminders that the person is dead.
4. Intense emotional pain (e.g., anger, bitterness, sorrow) related to the death. **(Note: This may be motivated in children and adolescents by feeling deprived of the person's help in responding to developmental needs.)**

Proposed Modifications: C

C. As a result of the death, at least 3 of the following symptoms have been experienced to a clinically significant degree, nearly every day, for at least the last month (continued):

5. Difficulty moving on with life (e.g., problems engaging with friends, pursuing interests, planning for the future). **(Note: In children, this may take the form of inability to achieve developmental milestones)**
6. Emotional numbness. **(Note: Young and school-age children may not understand or describe numbing. Adolescents may describe "not feeling anything")**
7. Feeling that life is meaningless. **(Note: Older children and adolescents may express this as "it's not worth trying," "nothing really matters anymore" or "my life is ruined")**
8. Intense loneliness (i.e., feeling alone or detached from others).

Proposed Modifications

One Proposed Text Note for the Development and Course Section of DSM-5-TR

The following proposed text note specifically refers to proposed PGD symptom B1 (intense yearning/longing for the deceased person) as it may manifest in bereaved children:

Young children may express yearning in thought or play as a wish to literally physically reunite with the deceased (e.g., to climb a ladder to heaven, or lie in the ground next to them). This reunion fantasy may sometimes take the form of a wish to die or fantasies of dying. However, it is not suicidal ideation stemming from feeling that one cannot go on without the person. Rather, young children's wishes or fantasies express, in concrete thinking, a way to overcome the painful physical separation (Kaplow, Layne, Pynoos, Cohen, & Lieberman, 2012). Adolescents can express suicidal thinking similar to reports in adults.

Learning Objective

4

Opportunities that a Psychiatric Disorder Can Bring to the Field of Child and Adolescent Bereavement

Opportunities PGD Can Bring to the Field

- If Prolonged Grief Disorder is formally adopted, there will be important opportunities to advance the field.
- Fact: PGD is simpler than PCBD in structure and number of symptoms required.
  - PGD: 1 “B” symptom (we recommend splitting into 2); 3 of 8 “C” symptoms.
  - PCBD: 1 of 4 “B” symptoms; 6 of 12 “C” symptoms (further partitioned into “Reactive Distress to the Death” and “Social/Identity Disruption;” plus Traumatic Bereavement Specifier.
- The upsides/potential downsides include:
  - **Upside**: It will be generally easier to conceptualize, assess, train, and educate our clients, the public, etc. about PGD than PCBD.
  - **Potential Downside**: It will not provide as rich, differentiated, and (perhaps) informative a picture of children’s grief reactions. We will have to rely more heavily on guiding theory.

Opportunities PGD Can Bring to the Field

Better diagnosis and assessment tools will enhance the capacity to:

- Differentiate between adaptive vs. maladaptive grief reactions (differential diagnosis).
- Distinguish between youth for whom supportive grief work is sufficient, vs. youth who may need specialized therapeutic services.
- Use brief but accurate screening tools to identify high-risk youth and refer them for in-depth assessment, potential treatment.
- Create integrated risk screening/referral networks that provide continuity of care across a range of intervention/treatment options.
- Case Conceptualization (PCBD was unwieldy, not very child friendly).

Opportunities PGD Can Bring to the Field

Grief Support Facilities

<u>Services:</u>

- **Risk screening**
- **Referrals** of youth who test positive to grief treatment facilities
- **Grief support services** (aim: facilitate adaptive grief reactions & positive adjustment)
- **Outcome evaluation** (individual cases)
- **Program evaluation**
- **Public advocacy and outreach**

Referrals

Grief Treatment Facilities

<u>Services:</u>

- **Risk screening**
- **Referrals** of youth who test negative to grief support services/facilities
- **In-depth assessment**, diagnosis
- **Therapeutic services** (dual aims: facilitate adaptive grief reactions & positive adjustment; reduce maladaptive grief reactions)
- **Outcome evaluation** (individual cases)
- **Program evaluation**
- **Public advocacy and outreach**

Continuity of Bereavement-Informed Care

Opportunities PGD Can Bring to the Field

Better diagnosis and assessment tools will enhance the capacity for:

- Clinical diagnosis (no longer provisional; officially diagnosable).
- Treatment planning (PCBD was unwieldy, not very child friendly).
- Treatment monitoring, assessing outcomes, program evaluation.
- Professional & paraprofessional training and education (dealing with a concrete diagnostic entity, not a provisional disorder likely to change).
- Naturalistic studies (stability of the diagnosis/prevalence estimates over time & across development).
- Cross-cultural studies (similar across cultural/racial groups? etc.)

Opportunities PGD Can Bring to the Field

Better diagnosis and assessment tools will enhance the capacity for:

- Public advocacy, prevalence of bereavement, prevalence of PGD.
- Sustainable funding streams, based on:
  - situation analysis (how many bereaved kids/families do we serve?),
  - needs assessment (how many kids need **supportive** services? How many need **therapeutic** services based on diagnostic prevalence rates?),
  - reliable improvement rates, program evaluation effect sizes (how many improve)? .
- Accessing treatment resources, clinicians will no longer need Adjustment Disorder as a proxy diagnosis. They can directly diagnose and treat PGD.

Opportunities PGD Can Bring to the Field

A diagnosis and well-designed assessment tools will make it possible to:

- Create a trio of widely-needed assessment tools:
  1. Self-report assessment tool (of PGD)
  2. Structured clinical interview of PGD (definitive "gold standard" diagnosis), used to create clinical cutoff scores that optimize:
     a. sensitivity (correctly including actual positives)
     b. specificity (correctly excluding actual negatives)
  3. Brief risk screening tool for PGD

Opportunities PGD Can Bring to the Field

A diagnosis and well-designed assessment tools will make it possible to:

- Estimate population-level prevalence rates of PGD.
- Estimate prevalence rates of bereavement and PGD in your particular setting (grief support facility/clinic/school system/hospital system/private practice).
- Base your assessment-driven clinical decisions on a true disorder rather than a provisional disorder (PCBD), a proxy disorder (adjustment disorder, depression, PTSD, anxiety, etc.), or no disorder.
- Use evidence-based assessment methods, which improve efficiency, precision, actionability. Evidence-based assessment helps you to hit the "assessment sweet spot:" Don't under-assess or over-assess; don't under-diagnose or over-diagnose.

Opportunities PGD Can Bring to the Field

A diagnosis and well-designed assessment tools will make it possible to:

- Integrate situation analysis (track bereavement prevalence rates) with needs assessment (track PGD prevalence rates). Not all bereaved youth need specialized services, but a significant portion often does, and it's good to know either way.
- Expand public outreach and advocacy beyond bereavement (a stressful life event) to include grief (reactions to that event).
  - Accurately estimating prevalence rates of mental health needs (PGD) in bereaved youth can parallel & support recent advances in estimating prevalence rates of childhood bereavement.
  - How many youth have unmet mental health needs relating to bereavement and grief?
    - In the general population?
    - In our setting/the clients we see and serve?
    - In our catchment area/region?

Learning Objective

5

How a Strength-Based Approach to Understanding Grief Can Raise the Standard of Bereavement Care

Risks/Criticisms of Adopting a Grief Diagnosis

- Adopting a “medical” model that emphasizes pathology and dysfunction rather than wellness and positive adjustment
- Pathologizing grief reactions per se (“grief symptoms”)
- Impacting young people’s self-concept (“I have a disorder”)
- Social stigma could be a barrier, make people reluctant to seek help
- Overdiagnosis of “normal” grief reactions
- Bias: selective attention to only some of a wide range of grief reactions, fail to validate normal/adaptive grief reactions
- Risk for missing important differences linked to culture, development, gender, race/ethnicity, relationship to deceased, circumstances of the death, etc.

Three Solutions to These Criticisms

1. Create a developmentally informed diagnosis that is sensitive to, and reflective of, the ways in which children and adolescents actually experience and manifest maladaptive grief reactions.
2. Create well-constructed assessment tools that are brief, reliable, valid, carry minimal risk of stigma, and are therapeutically actionable.
3. Create a strength-based theory of grief that:
   A. affirms the adaptive functions of grief,
   B. assists in differentiating between adaptive versus maladaptive grief,
   C. describes/explains the nature of individuals' distress and difficulties,
   D. prescribes interventions to reduce distress and improve functioning.

Overview of Multidimensional Grief Theory:

A Strength-Based, Positive Approach to Understanding, Assessing, and Intervening with Grieving Children and Families

The Origin of Multidimensional Grief Theory

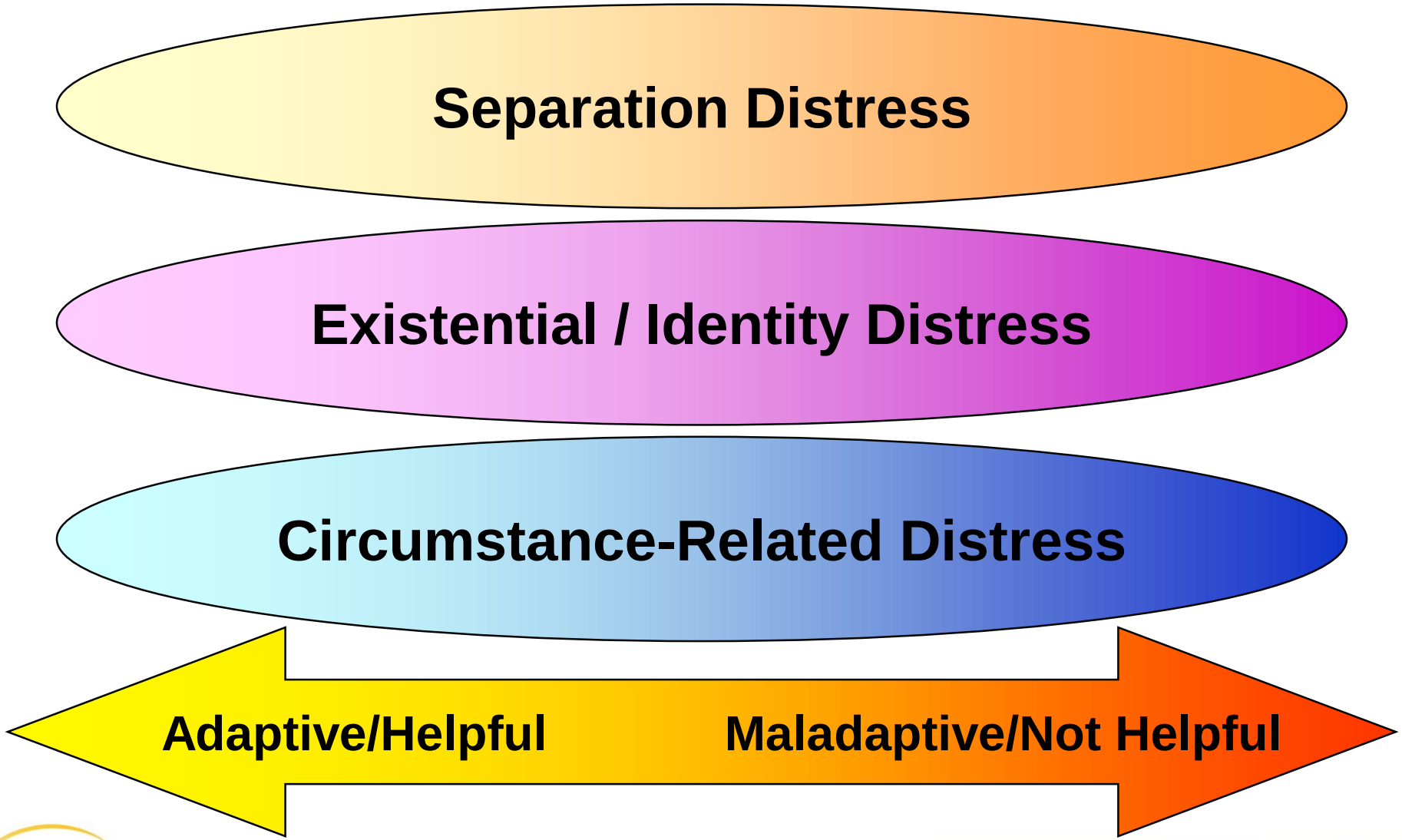
- Factor analysis of UCLA Grief Screening Scale (Layne et al., 1999) yielded two interpretable factors—Normal Grief and Maladaptive Grief.
- The two grief subscales differentially related to other variables.
  - Compared to normal grief, maladaptive grief correlated more strongly with nearly every distress indicator (PTSD, depression, somatic problems, family conflict, impaired school functioning, exposure to trauma reminders).
  - Compared to maladaptive grief, normal grief correlated more strongly (positively) with exposure to loss reminders and prosocial behavior.
  - (!!Eureka!!) I've discovered a different way to "unpack" and distinguish between adaptive/maladaptive grief! One that uses differential relations (differences in how variables relate to one another) as a tool for "dividing nature at its joints."

The Origin of Multidimensional Grief Theory

- Factor analysis focuses on internal consistency: It "unpacks" grief reactions solely on the basis of their internal correlations (insulated from surrounding ecological context).
- Differential validity matrix (Layne et al., 2011) emphasizes external consistency by unpacking grief reactions on the basis of their external correlations. It looks for clusters of variables that differentially relate to external indicators of positive vs. poor adjustment and partitions them into separate dimensions.
  - More ecologically anchored, enriched, and contextualized, draws on much more information than intercorrelations among grief reactions themselves.
  - Anchored to external metrics that matter—indicators of distress other than grief (e.g., depression), functional impairment, risky behavior, developmental progression, prosocial behavior. Better suited to predicting criterion variables, evaluating clinically significant change.
- These two methods of "unpacking" grief (etc.) are not mutually exclusive.

Multidimensional Grief Model

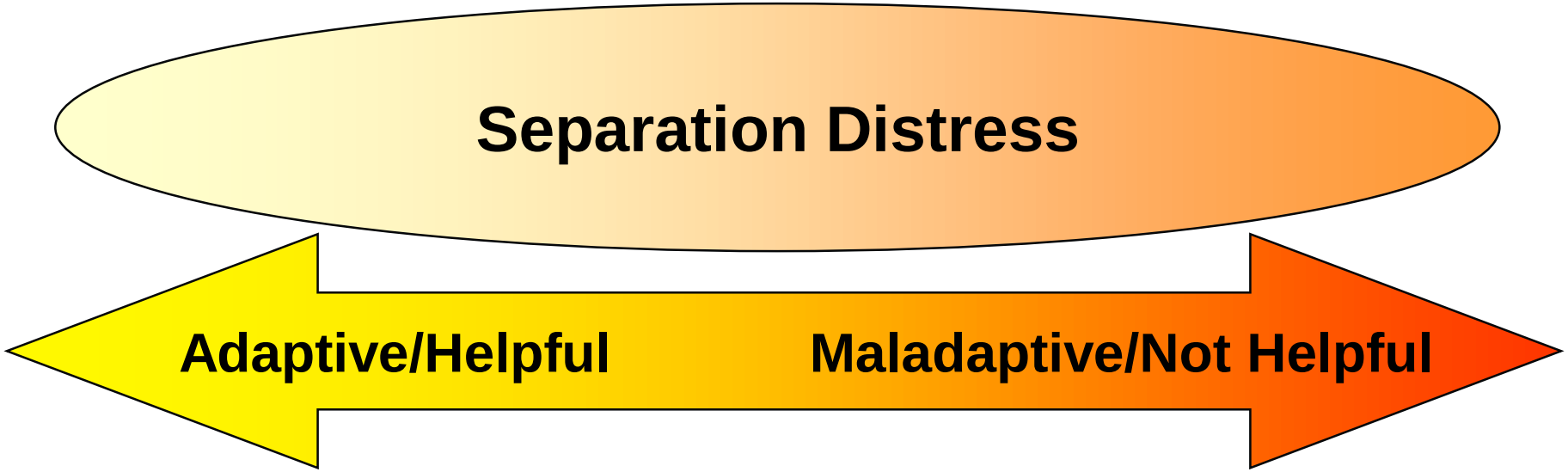
(Layne, Kaplow, & Pynoos, 2011; Layne, Kaplow, & Pynoos, 2012)



Central Challenge of Separation Distress

(Layne, Kaplow, Oosterhoff, Hill, & Pynoos, 2017

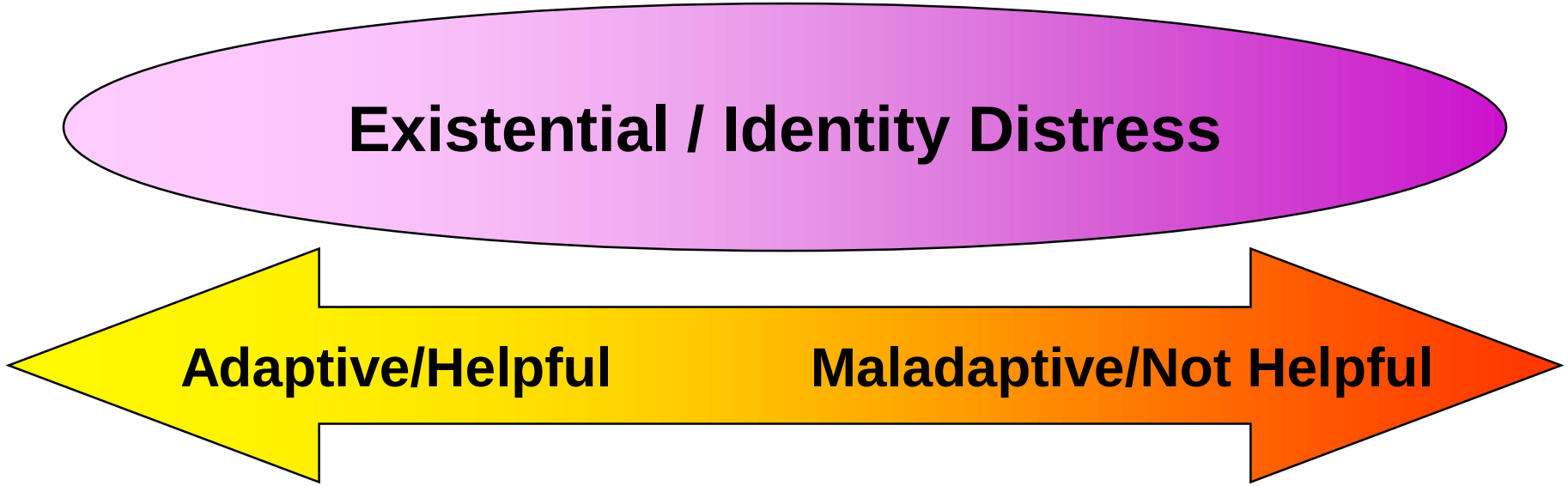
"How can I continue to feel connected to the person who died, so that they remain an important part of my life?"



Challenge of Existential/Identity Distress

(Layne et al., 2017

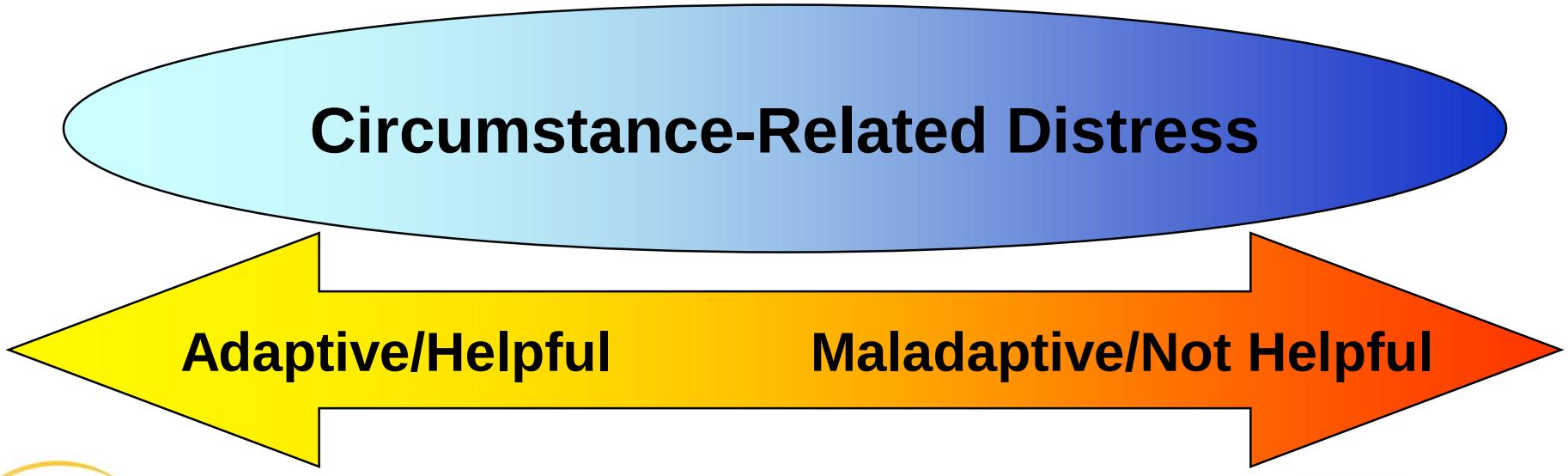
"Who am I as a person, and what is the purpose of my existence, now that this loved one is physically absent from my life?"



Challenge of Circumstance-Related Distress

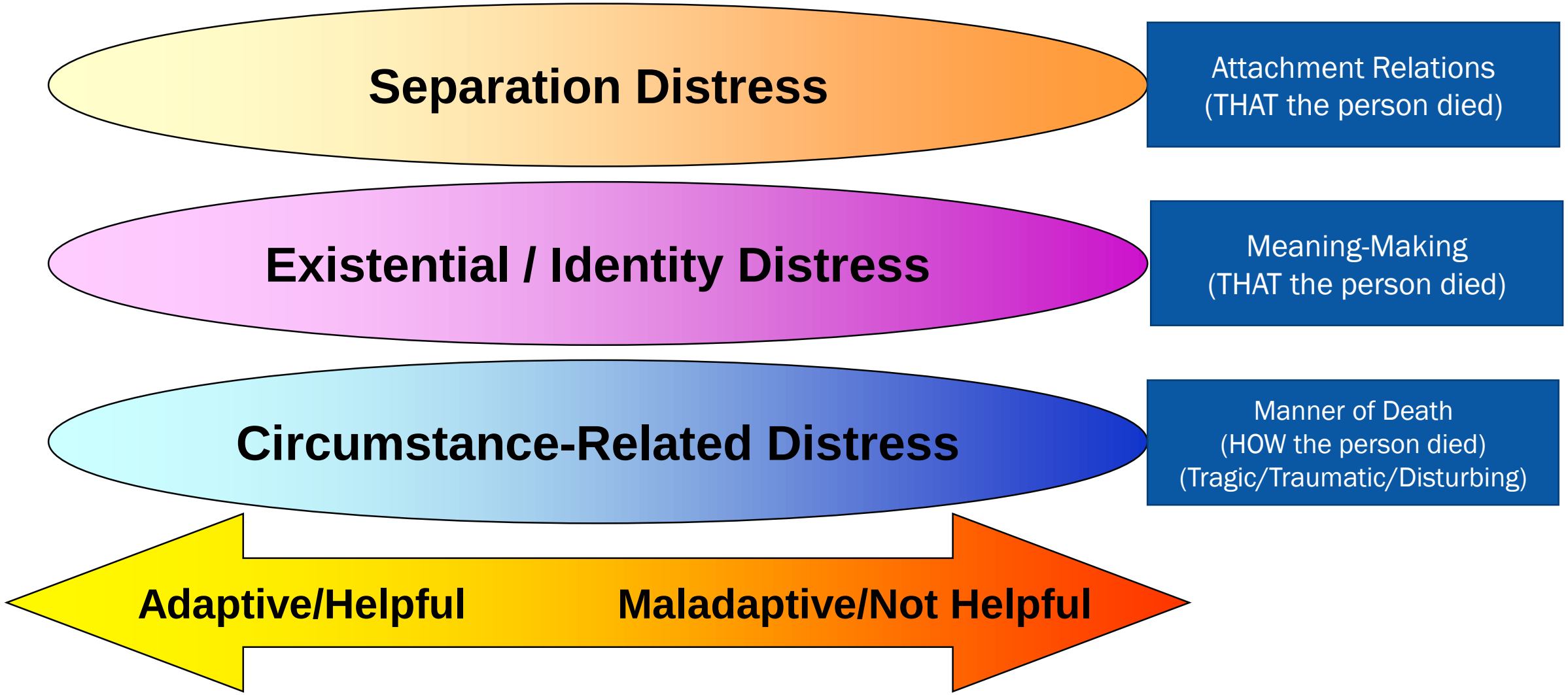
(Layne et al., 2017

"How do I manage my distressing thoughts, beliefs, wishes, fantasies, emotions, and impulses evoked by how this person died?"



Theorized Primary Origin of Maladaptive Grief Reactions

(Layne et al., 2017



A Multidimensional Framework is Important

(Layne et al., 2017

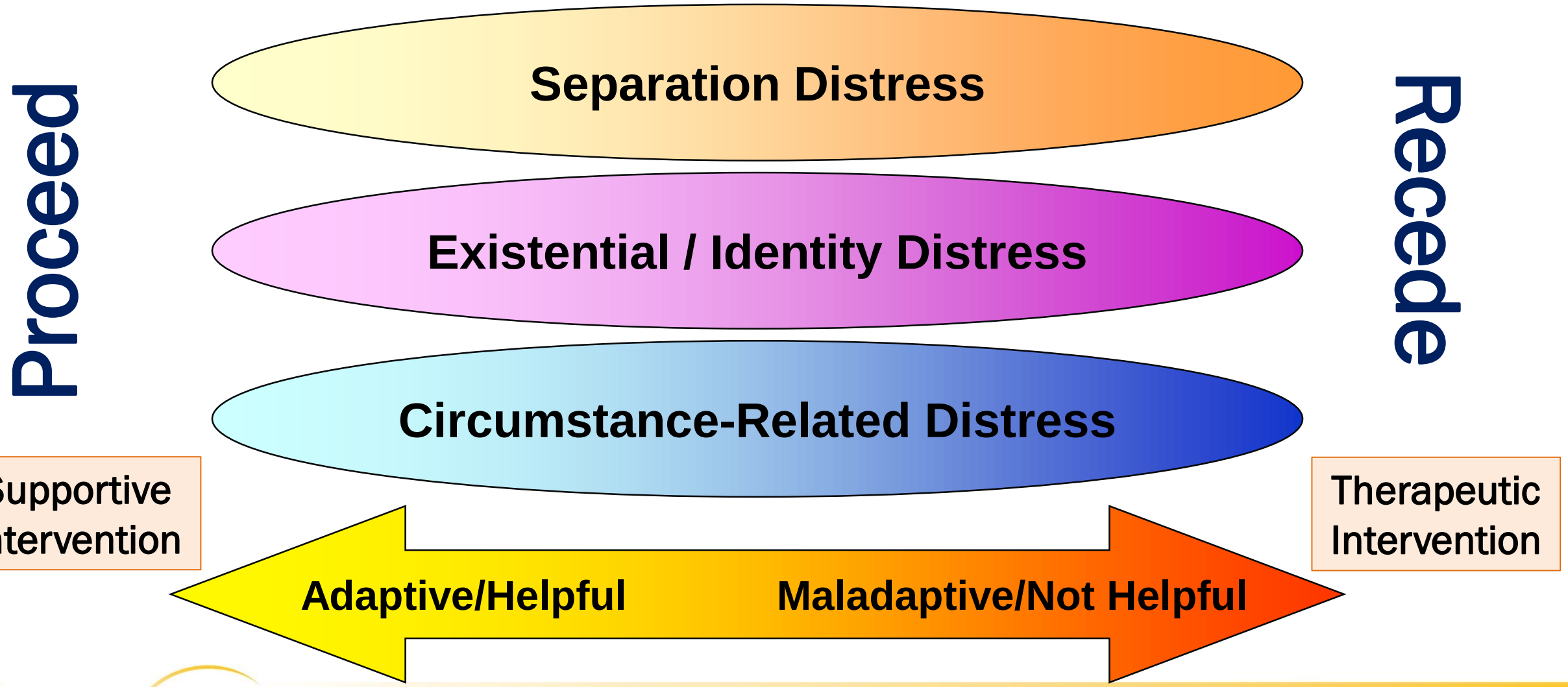
Different dimensions of grief may:

- be more prominent at different developmental stages (child vs. adolescent)
- differentially relate to different risk, vulnerability, protective factors (e.g., manner of death, exposure to the death, relationship to the deceased, exposure to reminders)
- be more prominent in some groups than others (e.g., type of death, culture, SES)
- differentially relate to different correlates & consequences (e.g., suicide ideation, depression, hopelessness, desires for revenge, risky behavior, prosocial activity).
- produce different grief profiles (supports individually tailored intervention)
- call for different treatment components/supportive interventions

Key Milestones in Multidimensional Grief Theory

- 1999: Developed method to unpack adaptive vs. maladaptive grief (Layne, Savjak, Saltzman, Pynoos)
- 2000: Unpacked, distinguished between existential/identity distress and circumstance-related distress (Layne, Savjak, Saltzman, & Pynoos)
- 2008: Began creating grief test item pool assessing both adaptive/maladaptive grief reactions within each conceptual domain (Layne & Pynoos)
- 2008: First clinical training in multidimensional grief model (Layne & Pynoos)
- 2011: Multidimensional grief theory, differential validity matrix first presented at a scientific conference (Layne, Kaplow, & Pynoos)
- 2013: Applied to military families (Kaplow, Layne, Saltzman, Cozza, & Pynoos)
- 2017: Applied to traumatically bereaved adolescents (Layne, Kaplow, Oosterhoff, Hill, & Pynoos)
- 2017: Integrated into a manualized intervention (Saltzman, Layne, Pynoos, Olafson, Kaplow, & Boat)
- 2019/2020: Applied to evidence-based assessment of bereaved youth (Layne & Kaplow, in press)

Integrating Grief Support with Grief Treatment



Opportunities PGD Can Bring to the Field

Grief Support Facilities

<u>Services:</u>

- **Risk screening**
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- **Program evaluation**
- **Public advocacy and outreach**

Continuity of Bereavement-Informed Care

Learning Objective

6

Empirical Evidence and Current Events Surrounding PGD

EVERMORE (founded & led by Joyal Mulheron)

- Bereavement care language to the US budget report.
- Directs key federal health agencies to report to Congress what bereavement care activities, if any, are being conducted at the agency level.
- Provision was advanced in the U.S. House of Representatives.
- Next up, the U.S. Senate.

To learn more about this provision, visit: https://docs.google.com/forms/d/1eLGjZvkbWNC9fbXeXfpDzrR60bvwkCMHQYpwo_Mou68/viewform?edit_requested=true

More information at www.live-evermore.org

What Have We Learned about DSM-5 PCBD in Bereaved Children and Adolescents?

Persistent Complex Bereavement Disorder (PCBD) works reasonably well for children/adolescents as gauged by:

- PCBD shows multidimensional structure in bereaved children/adolescents
- PCBD is linked to impaired functioning (with family, peers, at school)
- Growing evidence of test validity
- Significant improvement with grief-focused intervention
- Children can be good self-reporters under certain conditions
- Critical importance of developmentally appropriate wording, developmental vetting with experienced clinicians, iterative refinement (Kaplow, Layne, et al., 2018; Layne, Kaplow, & Pynoos, 2014)

(Layne, Kaplow, Oosterhoff, & Hill, 2019; Layne, Oosterhoff, Pynoos, Kaplow, & Pynoos, 2020)

What Types of Evidence Are Being Used to Evaluate the Validity, Reliability, and Clinical Utility of Proposed PGD Criteria?

What Types of Evidence Are Being Used to Evaluate Proposed PGD Criteria?

- What samples are used (Clinical? Community-based? Population-based/epidemiological?)
- Endorsement Rates (do bereaved youth report experiencing grief reactions often enough to be considered clinically significant?)
- Dimensionality :
  - Factor analysis
- Reliability
  - Cohesiveness (Cronbach's Alpha)
  - Incremental value added to scale cohesiveness (Alpha if Item Deleted)
  - Test-retest reliability
  - Inter-rater reliability (diagnostic agreement)
- Validity
  - Correlations with general health, impaired role functioning, impaired social functioning, depression, anxiety, PTSD
  - Predictive validity—predicts future health problems, suicide ideation
  - Incremental predictive validity
  - What number of C symptoms yields maximum correlation with measures of depression, PTSD?
  - What number of C symptoms yields maximum predictive validity with measures of depression, PTSD at a later point in time?
- Prevalence Rates of PGD (or its predecessor, PCBD)
  - 6-12 months post?
  - 12+ months post?

Test Reliability/Validity Evidence to Date

Key for Interpreting Columns 2 and 3 of the Following Tables:

- **Bolded entry:** We have **already** collected evidence to inform these questions. (Progress has been **made**.)

- **Blue font:** This type of evidence **could** be collected using current tools and methods (e.g., the PCBD Checklist), but the research has not yet been conducted, or is currently underway and not yet published. (Progress is **underway**.)

- **Red-tinted entry:** Limitations in the field (lack of an official diagnosis, lack of a structured interview, lack of a screening tool) prevent significant progress from being made in this area. (Sites for **future progress** if an official grief disorder is adopted.)

Test Validity Evidence to Date: Screening, Assessment, and Diagnosis

How Does this Advance the Field?

- The following three tables are not only a stewardship report of what my colleagues and I have been doing to help advance the field.
- They are also a guide to help prospective test users become informed consumers by knowing what to look for when “shopping” for assessment tools for bereaved youth.

How Does This Advance The Field? (cont.)

1. Tests are constructed to answer specific types of questions (listed in the left table columns).
2. Answering a given assessment question constitutes an **application** of that test.
3. A test should be **validated** for each specific application for which it is used.

How Does This Advance The Field? (cont.)

4. Test construction involves planning the specific applications a test will be used for and building those into the test construction procedure. Examples of these applications and desirable "built in" features include:
   a. Risk screening? Brevity and classification accuracy.
   b. Case formulation? Treatment planning? Good content coverage of the full spectrum of grief reactions. This will provide an accurate representation of each client's individual grief reactions. This detailed profile can be used to support feedback on assessment results, individualized psychoeducation ("my therapist really gets me!") and treatment tailoring.

How Does This Advance The Field? (cont.)

5. Test validity evidence (middle columns) offers a rationale and empirical justification for the use of the test for that application.
6. “Shopping” for a test should thus involve:
   a. Specifying the question you want to have answered.
   b. Recognizing that each question is a test application.
   c. Searching for a test designed (both in test construction procedure and accompanying validity evidence) for those applications. (right column).

Type of Clinical Decision or Question	Reliability/Validity Evidence Needed	Tools/Evidence Gathered to Date
• Can PCBD/PGD be assessed **reliably**? • Is PCBD/PGD a **valid** diagnosis? • Is it **related** to other disorders and to functional impairment? • Is it **distinct** from other related disorders? • Can it be assessed in **developmentally appropriate** ways? • Can it be assessed in **culturally appropriate ways?** • Can it be assessed with good **classification accuracy**? (don't overdiagnose, don't underdiagnose?)	• **Construct validity** • **Factorial validity** • **Convergent validity** • **Discriminant validity** • **Discriminant-groups validity** • **Differential validity** • **Content validity ratio** • Test-retest reliability • Factorial invariance • Inter-rater reliability • Sensitivity/specificity	• Geronazzo, Fan, Duarte, Layne, et al., (2019) • Hill, Kaplow, Oosterhoff, Layne (2019) • Kaplow, J.B., Layne, C. M., Oosterhoff, et al., (2018). • Layne, Kaplow, & Pynoos (2014) • Evidence pending re: test-retest • No evidence available re: -inter-rater reliability (diagnosis) -sensitivity/specificity (risk screening tool accuracy)
• How **prevalent** is PCBD/PGD in the general population? • Can it be assessed **efficiently** and **accurately** with risk screening tools?	• Good test item discrimination (item response theory) • Sensitivity/specificity (receiver operating characteristic curve)	• No "gold standard" structured interview is available • No screening tool is available • No self-report assessment tool is available
• How **prevalent** is PCBD/PGD in our specific population(s)/setting? • Can it be assessed **efficiently** and **accurately** with screening tools? • Can we **identify/refer** high-risk clients?	• Good test item discrimination (item response theory) • Sensitivity/specificity (receiver operating characteristic curve) Predictive validity	• Kaplow, J.B., Layne, C. M., Oosterhoff, et al., (2018) (clinic prevalence estimate) • No screening tool is available

Test Validity Evidence to Date: Treatment Planning

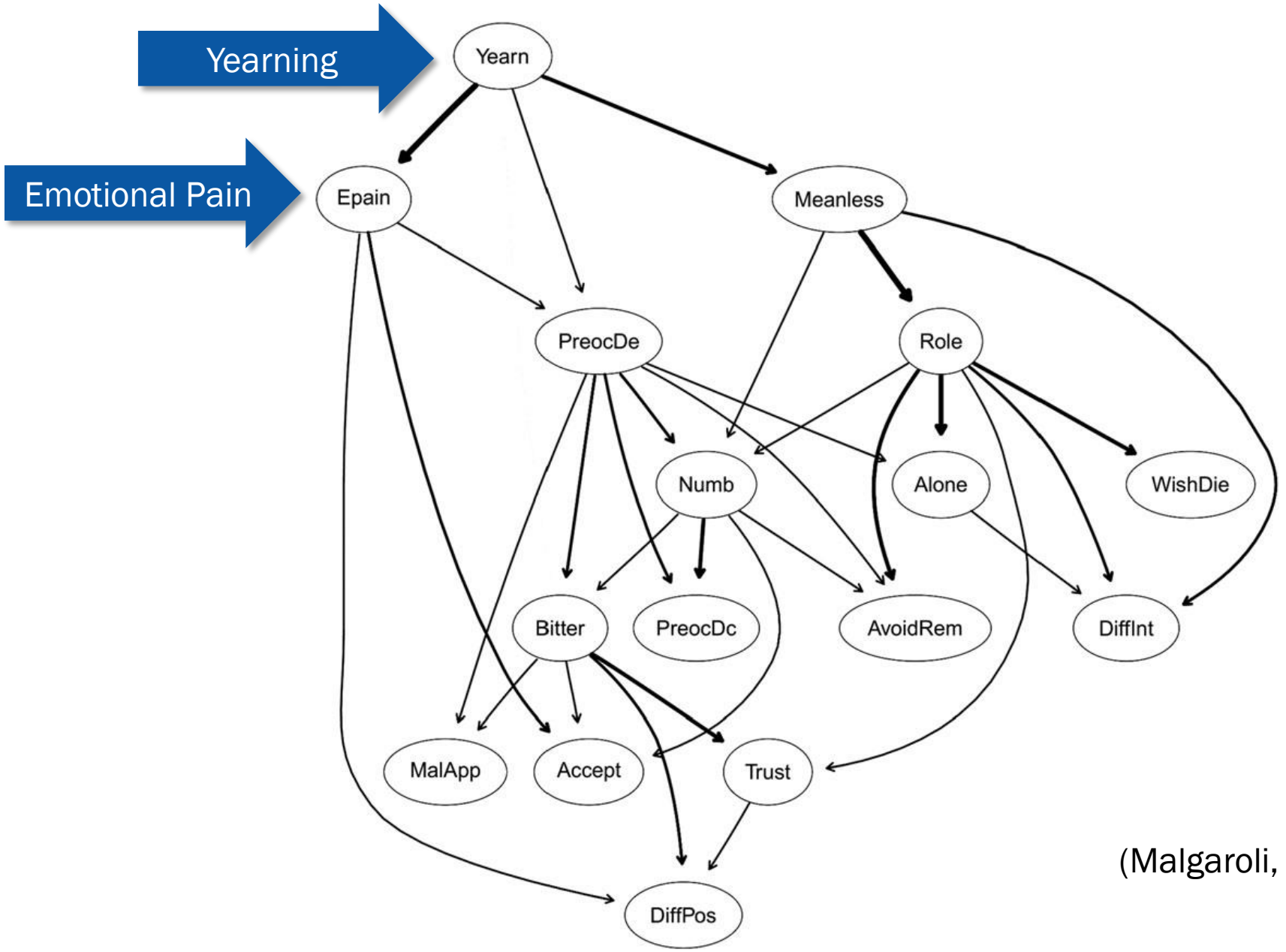
Type of Clinical Decision or Question	Type of Reliability/Validity Evidence	Evidence to Date
• How do we **match** clients to optimal treatment options? (e.g., treat PTSD? Grief? Depression?) • How do we **select** which treatment components to use? (e.g., TGCTA Modules 1, 2, 3, or 4)? • How do we **prioritize and sequence** our interventions? • How do we ensure that we don't **overprescribe** treatments (reduces efficiency, increases risk for iatrogenic effects)?	• Reliable Change Index • Predictive validity • Incremental predictive validity • Differential validity	• Grassetti, Herres, Williamson, Yarger, Layne, & Kobak, R. (2014). • Grassetti, Williamson, Herres, Kobak, Layne, Kaplow, & Pynoos (2018). • Herres, Williamson, Kobak, Layne, Kaplow et al. (2017). • Hill, Oosterhoff, Layne, Rooney, Yudovich, Pynoos, & Kaplow (2019).
• How do we **prioritize and sequence** our targeted treatment outcomes (e.g., PTSD before grief)? • How do we **tailor** our intervention (selecting specific exercises, etc.) to match our client's needs, strengths, development, culture, preferences?	• Reliable Change Index • Predictive validity • Incremental predictive validity • Differential validity	• Grassetti, Williamson, Herres, Kobak, Layne, Kaplow, & Pynoos (2018). • Hill, Oosterhoff, Layne, Rooney, Yudovich, Pynoos, & Kaplow (2019). • Layne et al., 2001; 2008

Test Validity Evidence to Date: Treatment Evaluation

Type of Clinical Decision or Question	Type of Reliability/Validity Evidence	Evidence to Date
• How do we **monitor** client response to intervention? • How can we tell whether they are getting better, worse, or not changing?	• **Pre-post change (effect size)** • Sensitivity to clinical change • **Reliable Change Index**-(standard error of the difference between scores)	• Hill et al., (2019)—improvement after Phase I of Multidimensional Grief Therapy (MGT, more improvement after Phase II of MGT
• How do we **surveil** our clients for new/recurring life difficulties? • If our clients are not getting better (or are getting worse), could it be due to new or recurring life adversities?	• **Content validity** (screening tools for life adversities must cover common life adversities, have options for detecting rare but significant life adversities)	• Pynoos, Steinberg, Layne, et al. (2014)
• How do we measure **statistically significant change** in client outcomes? • (i.e., How do we evaluate whether client outcomes are not simply due to chance—random fluctuations?)	• **Standard multivariate analyses** • **Effect size** (group outcome level) • **Reliable Change Index -reliable improvers** (individual-case level)	• Grassetti et al., 2014 • Herres et al., 2017 • Hill et al., in press • Layne et al., 2001 • Layne et al., 2008 • Saltzman et al., 2001
• How do we measure **clinically significant change** in client outcomes? • (i.e., How do we tell whether this change meaningfully improves my client's life?)	• **Improvement in role functioning** • **Improvement in relationships** • Reduction in risky behavior • Improvement in well-being	• Davies et al., 2007 • Layne et al. (2001) • Layne et al. (2008) • Saltzman et al. (2001)
• How do we check for **iatrogenic outcomes** (worsened outcomes)?	• **Reliable Change Index–reliable deteriorators** (individual-case level)	• Hill et al., (2019) • Layne et al. (2008)

Q: Is Multidimensional Grief Theory Compatible with Adult Grief Reactions?

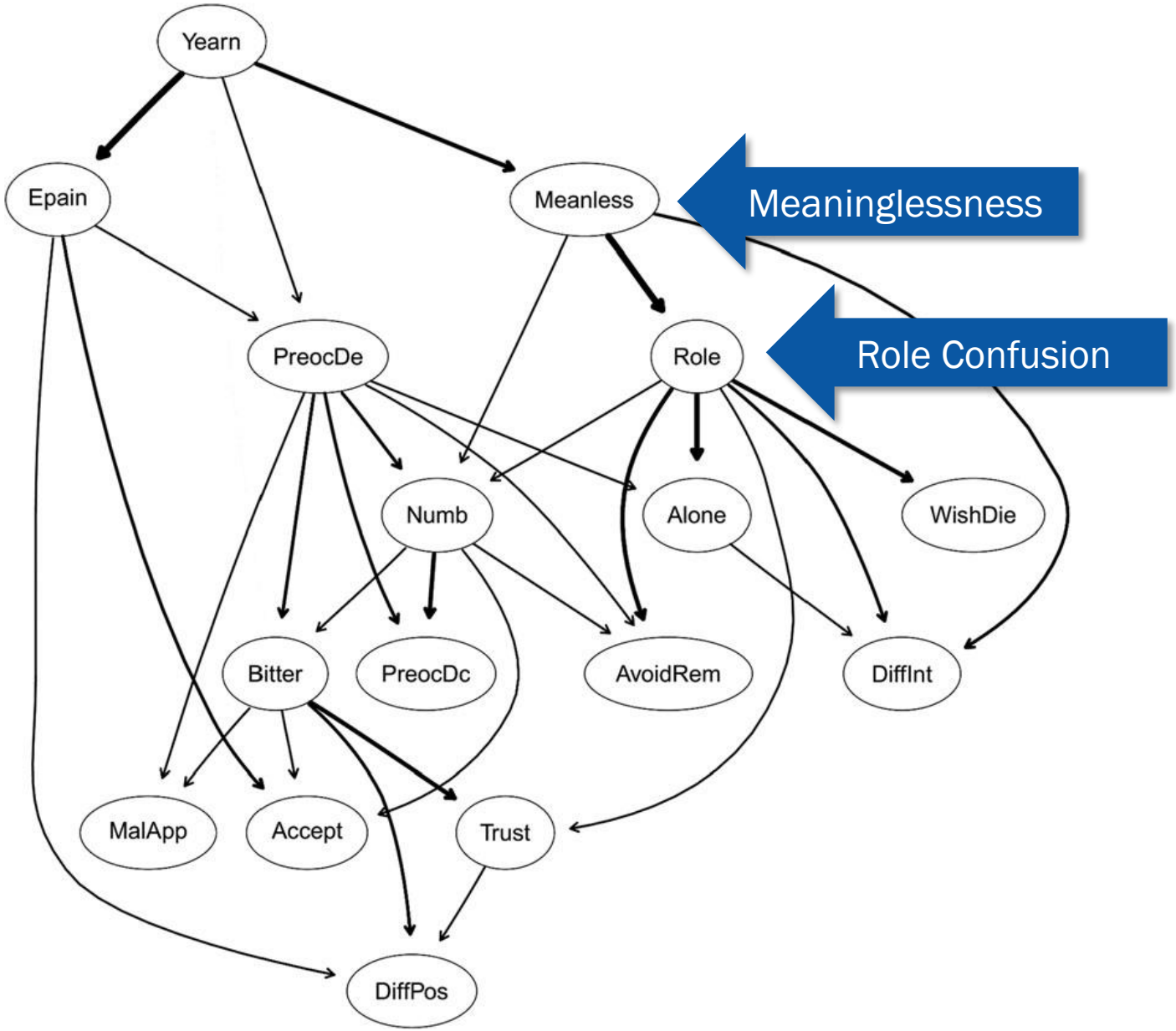
*Figures Drawn from a Longitudinal Network Analysis of Grief Reactions over Time in Bereaved Adults (Malgaroli, Maccallum, & Bonanno, 2018)



Separation Distress

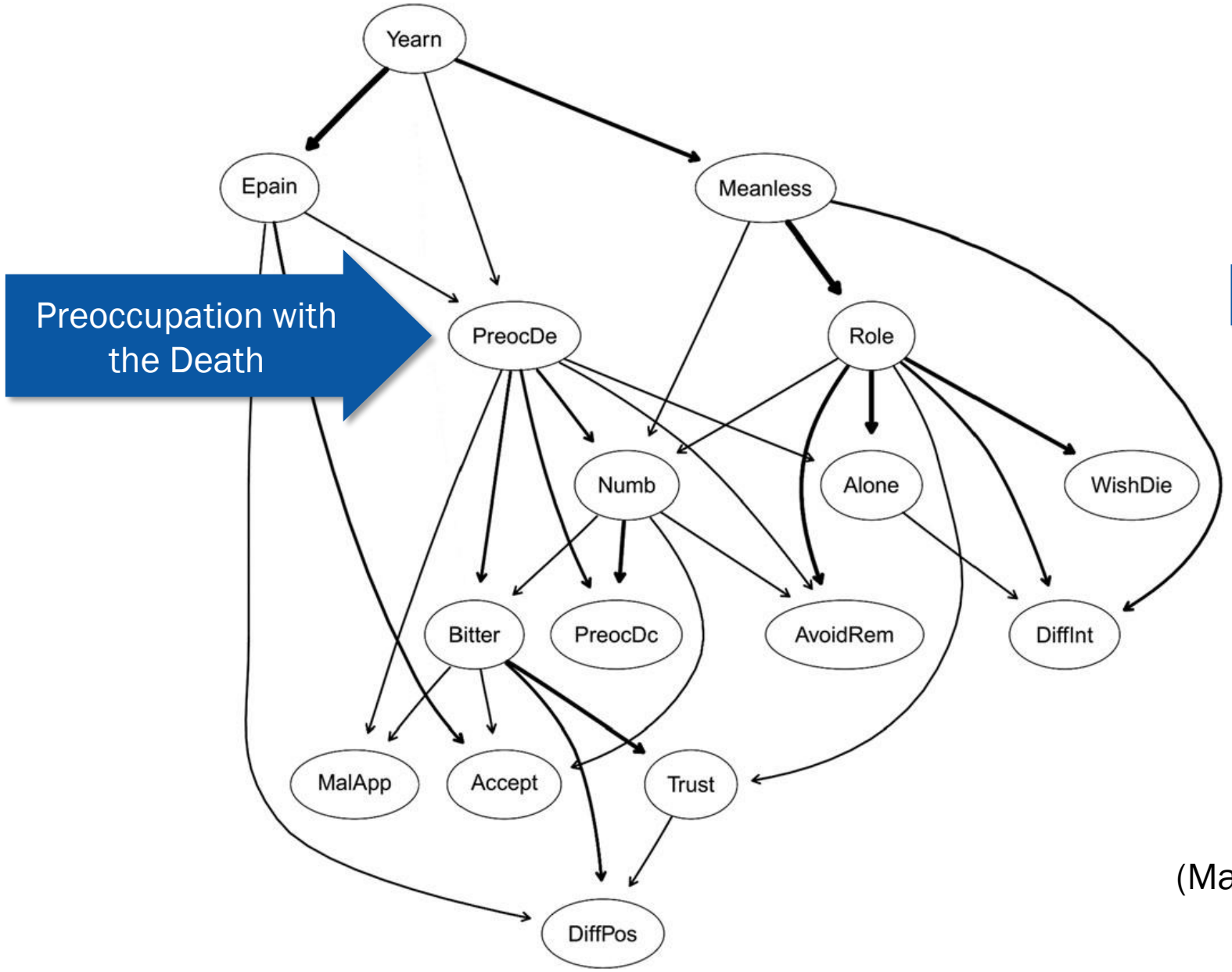
(Malgaroli, Maccallum, & Bonanno, 2018)

Existential and Identity Distress (Identity Disruptions, Existential Crises)



(Malgaroli, Maccallum, & Bonanno, 2018)

Circumstance-Related Distress



(Malgaroli, Maccallum, & Bonanno, 2018)

Q: Is Multidimensional Grief Theory Compatible with Adult Grief Reactions?

Answer: It Appears So.

(We assess the same broad spectrum of grief reactions in bereaved youth and their adult parents/primary caregivers)

Wrap-Up

1. American Psychiatric Association DSM-5-TR Website where you can advocate for developmental modifications to prolonged grief disorder:

   https://bit.ly/dsm-5-proposed-changes

2. Evermore website, where you can learn more about how to advocate for bereavement-informed policies with lawmakers:

   https://bit.ly/2WCJvip (general advocacy)

   https://bit.ly/3brqvHV (2020 congressional letter requiring bereavement reporting)

3. Recording of this webinar on Prolonged Grief Disorder plus supporting materials on NCTSN.org:

   https://bit.ly/2Ug6Ch5 (webinar)

   https://bit.ly/2UdKbZT (web page)

Questions?

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- ResearchGate website: https://www.researchgate.net/profile/Christopher_Layne
- Trauma and Grief Component Therapy for Adolescents (TGCTA) website: http://tgcta.com/

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