Developmental Perspectives on DSM-5-TR Prolonged Grief Disorder Criteria: Proposals for Improvement

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<u>Reference Citation:</u> 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).

Slide	Text
1	Let me first disclose that I am an author of Trauma and Grief Component Therapy for Adolescents (Saltzman,
	Layne, Pynoos, Olafson, Kaplow, & Boat, 2017), lead author of the Persistent Complex Bereavement Disorder Checklist
Developmental Perspectives on DSM-5-TR Prolonged Grief Disorder Criteria: Proposals for Improvement Chistopher M. Layne, Ph.D. Julie B. Kaplow, Ph.D., ABP Benjamin Gosterhoff, Ph.D. Ryan Hill, Ph.D. **Control Region, of Non Bounds To an equation, None or of the North Act of the Section of the North Act of the	Layne, Pynoos, Olafson, Kaplow, & Boat, 2017), lead author of the Persistent Complex Bereavement Disorder Checklist (Layne, Kaplow, & Pynoos, 2014), and lead developer of multidimensional grief theory (Layne, Kaplow, Oosterhoff, Hill, & Pynoos, 2017), which I first began to build in the late 1990's as a UNICEF post-doctoral fellow inspired by the work of Selby Jacobs and Holly Prigerson. I will be discussing each of these today. I am part of a clinical research team who have been utilizing a multidimensional theory of child and adolescent bereavement reactions to understand, assess, and treat bereaved youth. This theory explicitly acknowledges the presence of both adaptive and maladaptive grief reactions to the loss of a loved one or close friend. With Dr. Julie Kaplow, I am currently a Co-PI of a NY Life Foundation-funded multi-state practice research network, currently comprised of eleven sites, that provide a range of clinical and/or supportive counseling services to bereaved children and adolescents (hereafter youth) and their families. The practice research network is built on a set of "common denominator" components, including a common conceptual model of grief (multidimensional grief theory), a common set of assessment tools (e.g., the PCBD Checklist), a common manualized intervention (Trauma and Grief Component Therapy for Adolescents; Saltzman, et al., 2017), and a common set of training materials. The PCBD Checklist is the seventh iteration of a set of grief measures my colleagues and I first began implementing in post-war Bosnia in the late 1990's (e.g., Layne & Pynoos, 1997) and have successively refined since that time (e.g., Layne, Kaplow, & Pynoos, 2013). The Checklist is our most rigorously-constructed test to date (Kaplow, Layne, et al., 2018; Layne et al., 2014). Our advancements in test construction have co-evolved with our advancements in building an aultidimensional theory of grief, which I have been training on for over 10 years (Layne & Pynoos, 2008), and building an assessment-driven, m
	perspectives.

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My presentation draws in part on early field work my colleagues and I conducted in Los Angeles (Layne, Pynoos, & Cardenas, 2001; Saltzman et al., 2001); post-war Bosnia with UNICEF (Layne et al., 2001; 2008), in New York City following the September 11th 2001 terrorist attacks (Hoagwood, Layne, et al., 2010), as well as later work in Delaware, Ohio, Michigan, Texas, Minnesota, and other locations. During this more than 20-year period my colleagues and I have been building a multidimensional formulation of grief and using it as a foundation for an assessment-driven, modularized treatment (Saltzman et al., 2017) with the aim of maximizing its flexibility and clinical utility for bereaved and traumatically bereaved youth. This work continues with evaluation studies of high-risk youth in Delaware (Grassetti et al., 2014, 2018; Herres et al., 2017), Ohio (Olafson et al., 2016), in Ann Arbor and Detroit MI, and Houston TX (Hill et al., in press), including the Houston Independent School District (one of the nation's largest, comprised of 288 schools). For the last 3 years, our work has centered on building an 11-site New York Life Foundation-funded practice research network, as well as the ongoing clinical work being conducted, disseminated, and evaluated through Dr. Kaplow's Trauma and Grief (TAG) Center at Texas Children's Hospital and in local children's grief camps. We have taken the APA invitation to investigate DSM-5 provisional Persistent Complex Bereavement Disorder (PCBD) criteria very seriously since being invited to write a review for the DSM-5 subworking group on PCBD (Kaplow, Layne, Pynoos, et al., 2012). The resulting paper has drawn great international interest, with well over 12,000 downloads to date.

In this presentation, I will argue that a multidimensional approach not only more accurately reflects how grief reactions manifest in bereaved youth, but also facilities a balanced, strength-based, and problem-focused grief profile for bereaved youth that clinicians, grief support facilities, youth, and families prefer. As previously noted, the origins of this theory precede PCBD by more than 15 years, beginning with our field work in the aftermath of the Bosnian Civil war and the September 11th terrorist attacks. My colleagues and I propose that multidimensional grief theory subsumes all primary features and clinical manifestations of PCBD while also explicitly bringing in an adaptive counterpart that greatly facilitates the integration of strength-based grief support and positive youth development-focused work. We have field-tested this theory in many clinical trainings around the country, in constructing assessment tools, writing treatment manuals, and building training curricula. It carries clinical utility, guiding intervention that is flexibly tailored to youths' individual grief profiles. We propose that, as a diagnostic construct, PCBD has within it the makings of a multidimensional diagnosis, which multidimensional grief theory makes more explicit and clinically actionable.



Slide 2 provides a model derived from multidimensional grief theory (Layne, Kaplow, & Pynoos, 2012). We have applied this model to diverse populations, including inner-city youth (Hill et al., in press; Saltzman et al., 2001), war-exposed youth (e.g., Layne et al., 2001; Layne et al., 2008), youth exposed to terror attacks (Hoagwood, Layne, et al., 2010), Native American youth (Layne & Pynoos, 2008), juvenile justice-involved youth (Olafson et al., 2016), traumatically bereaved adolescents (Layne et al., 2017), and military families (Kaplow, Layne, Saltzman, Cozza, & Pynoos, 2013). The model depicts a multidimensional approach to understanding, assessing, and intervening with grief in both directions (horizontally and vertically). Let me call attention to four distinguishing features of the model.

A first feature is that **the model is multidimensional along the horizontal axis**, in that it acknowledges that grieving and mourning are, in most cases and settings, fundamentally normal, healthy, and adaptive processes. This is represented by the Adaptive/Helpful vs. Maladaptive point of distinction lying at the base of the model. It thus **explicitly recognizes**, **and distinguishes between, adaptive versus maladaptive grief reactions.** We have empirically replicated this basic distinction across multiple data sets gathered in post-war Bosnia, New York City, and our practice research network.

- a. Note that this distinction between adaptive vs. maladaptive reactions is **only conceptual.** It is not a true continuum, in that the dimensions are neither mutually exclusive nor inversely correlated.
- b. Instead, multidimensional grief theory posits that **adaptive and maladaptive grief reactions can, and frequently do, co-occur and covary**. For example, we have observed shifts from intense emotional pain to
 comforting reminiscing in the same youth in a matter of minutes, even seconds. We have also consistently found
 that theorized maladaptive grief reactions correlate positively (typically within the moderate range) with
 theorized adaptive grief reactions—an impossibility in a true continuum, such as a temperature thermometer.

A second feature is that the model is <u>multidimensional</u> along the vertical axis, in that it proposes that a variety of different grief reactions can arise following the death of a loved one (Layne et al., 2017; Layne, Kaplow, & Pynoos, 2013). Multidimensional grief theory postulates three primary conceptual dimensions (while acknowledging that other types of reactions, as well as complex combinations of these reactions, can also arise). These dimensions consist of:

- a. <u>Separation Distress</u>, characterized by reactions such as missing the person who died, pining for their return, yearning for their presence, protest over the separation, and longing to be physically reunited with them.
- b. **Existential/Identity Distress**, characterized by either a sense of **disrupted personal identity** (feeling like part of you died with the deceased, feeling like you're a different person since the death), experiencing a sense of historical discontinuity; or a personal **existential crisis** (**e.g.**, losing your reasons for living, giving up positive future aspirations, and feeling like your life is irreparably blighted due to the loss).
- c. <u>Circumstance-Related Distress</u>, which involves distress over the particular manner of death. This may be involve distress over **traumatic deaths** (e.g., accidents, homicides). However, we strongly disagree that such distress necessarily constitutes PTSD, as we have encountered many youth who are highly distressed by deaths that cannot be classified as traumatic, including deaths by natural causes. Examples of this intense distress include deep sadness that they died young, died alone, feeling like they deserved a better death, not being able to say goodbye, having them die with unresolved hard feelings, feeling like you contributed to their death, senseless or meaningless deaths, preventable deaths (e.g., due to negligence), or feeling angry at them for not taking better care of themselves (e.g., regular medical check-ups) (Saltzman et al., 2017).

A multidimensional framework is important because: (Layne et al., 2017)

Different grief-related features may:

- -be more prominent at certain developmental stages
- -differentially relate to specific risk or protective factors
- (e.g., loss reminders vs. trauma reminders)
- -differentially relate to causal consequences (e.g., suicide ideation)
- -not be present in all bereaved groups (e.g., culture, age)
- -call for different treatment components or supportive interventions

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A third feature is that the model carries direct implications for clinical assessment and intervention. Each grief dimension carries its own associated risks, coping challenges, intervention objectives, and intervention practice elements (Layne, Kaplow, et al., 2017; Saltzman et al., 2017). Based on early findings that grief correlates more strongly with loss reminders, while PTSD correlates more strongly with trauma reminders (Layne et al., 2006), and that different types of trauma exposure (e.g., traumatic deaths vs. life threat) exert differential effects through different pathways of influence (Layne et al., 2010), I began to collaborate (most notably with methodologists Joseph Olsen, Marit Netland, and Alan Steinberg) to develop an empirical method for differentiating between different dimensions of grief. The method draws distinctions between different dimensions of grief (and other constructs such as PTSD) on the basis of how they differentially relate to external criterion variables, such as different risk factors and different treatment components (Layne, Kaplow, Netland, Steinberg, & Pynoos, 2014). This method, termed the differential validity matrix, is the primary conceptual and empirical engine that underlies our approach to drawing conceptual distinctions that make a real-life difference. Examples include differentiating between adaptive versus maladaptive grief reactions, differentiating between grief versus PTSD, and prescribing different grief treatment components depending on which grief dimensions are elevated (Saltzman et al., 2017). Core propositions of multidimensional grief theory arise as direct implications of the differential validity matrix approach. These propositions form the foundation of our method for screening and triaging youth using their risk profiles, constructing multidimensional measures, unpacking PTSD and grief as related but distinct consequences of trauma and bereavement, and tailoring intervention according to youths' assessment profiles. Specifically, multidimensional grief theory proposes that different dimensions of grief may **differentially relate to different** (Layne et al., 2017):

- risk and protective factors (e.g., different types of deaths, relationship to deceased)
- consequences (e.g., school impairment, risky behavior, suicide ideation)
- correlates (e.g., PTSD, depression, anxiety)
- moderator variables (gender, age, race, culture/ethnicity, SES, prior history)

And most relevant to assessment and clinical practice, that different dimensions of grief may:

- be more prominent at different developmental stages (e.g., separation distress among children, existential/identity distress among adolescents)
- not be equally present in all bereaved populations (e.g., Detroit vs. Houston vs. Los Angeles)
- call for different treatment components—a topic I will return to later as I discuss our flexibly-tailored, modularized treatment approach for bereaved and traumatically bereaved youth (Saltzman et al., 2017).

We propose that this adaptive/maladaptive framework carries multiple advantages, including (a) affirming that most grief reactions occur within the adaptive/healthy range, (b) acknowledging the role of caregiver facilitation in influencing children's adaptive/maladaptive grief reactions, and (c) facilitating the integration and continuity of care between general grief support facilities and clinical/therapeutic intervention facilities.

Test Construction: The Persistent Complex Bereavement Disorder (PCBD) Checklist

- · Theoretically-derived, multidimensional conception of child and adolescent grie

- Validated on youth ages 7 to 18 across various populations (e.g., Ann Arbor, Detroit, Houston, San Antonio, Baton Rouge, Atlanta)
- (N = > 500, diverse samples, 10 clinicians, multiple years iterative refinement

A fourth feature of the model is that it supports developmentally sensitive test construction (Kaplow, Layne, et al., 2018; Layne, Kaplow, & Pynoos, 2014). Our prior work revealed that grief items adapted from adult measures were often difficult for children to understand (Kaplow, Layne, & Pynoos, 2014; Nader & Layne, 2009). We thus pursued a "bottom up" developmentally-grounded approach to constructing our own test item pool, which began with generating child-friendly test items (Layne, Kaplow, & Pynoos, 2013). We recruited national content experts to rate each item for content validity. We then enlisted clinicians to rate the items for clinical utility and developmental appropriateness, conduct youth focus groups to review items for acceptability, suggest more kid-friendly wording as needed, and administer the items at summer grief camps (Kaplow, Layne, & Pynoos, 2014). We then re-worded and iterated the test items numerous times, eventually with over 500 bereaved youth and 10 skilled clinicians as test administrators. We adopted "the uncanny look" in youth's faces as our aspirational standard for developmental appropriateness. That is, we sought to iterate test item wordings until the child's expression reflected a "How did you know that about me?!" look, as if they were mystified as to how the interviewer could know their inner experiences (Kaplow, Layne, et al., 2018; Layne, Kaplow, & Pynoos, 2014).

These observations lead to our first recommendation: A Multidimensional conceptual framework allows for a more differentiated clinical profile and better support for assessment, training, case formulation, treatment planning, and monitoring outcomes. This should be retained in a grief diagnosis moving forward.

This slide presents demographic information on the sample we used in our first published validation study of the PCBD Checklist (Kaplow, Layne, Oosterhoff et al., 2018). Note the large number (> 500) and diversity in age and circumstances of the death.

In the remainder of this presentation, let me share some hard-won lessons our team has learned over the years while constructing and validating the PCBD Checklist using data gleaned from the practice research network and the TAG clinic.

Mean age = 13.49 (range = 8 to 18) Race/Ethnicity: African American = 46% Caucasian = 39% Biracial = 6.5% Hispanic = 2.5% Asian = .8%

N = 367 (from Houston and Detroit)

Other = 4.8%

5 Data from our GIFT Network

6 What Have We Learned about PCBD in Bereaved Children and Adolescents?

PCBD works reasonably well for children & adolescents as

- 1. Multidimensional structure yields Good Model Fit (CFA)
- 2. Links to functional impairment (family, peers, school)
- 3. Growing evidence of test validity
- 4. Positive response to grief-focused intervention
- 5. Children can be good self-reporters under certain conditions
- 6. Critical importance of developmentally appropriate wording, developmental vetting with experienced clinicians, iterative (Kaplow, Layne, et al., 2018; Layne, Kaplow, & Pynoos, 2014)

We may be alone among the three teams presenting at this workshop in asserting that, from a child and adolescent perspective, PCBD is performing reasonably well. We wish to propose the retention of certain features in a formal grief diagnosis that we consider clinically, theoretically, and empirically valuable, while also recommending some fairly modest developmental modifications.

Although our developmentally-grounded test item pool (now comprised of over 80 items; Layne, Kaplow, & Pynoos, 2013) also includes a broad array of adaptive grief reactions, we have been actively studying and applying PCBD as a provisional diagnostic entity. Specifically, our data allow us to evaluate not only the psychometric properties of the PCBD Checklist, but also the clinical utility of PCBD as a diagnostic construct in guiding the development of a manualized treatment built on a multidimensional framework, training and consulting with or supervising around 200 grief counselors around the country, and the utility of PCBD in case formulation, treatment planning, monitoring treatment response, and assessing treatment outcome. Let me review some selected findings from our studies to date in terms of specific types of empirical evidence (Grassetti, Herres, et al., 2014; Grassetti, Williamson, et al., 2018; Herres et al., 2017; Hill, Oosterhoff, et al., in press; Hill, Dodd, et al., in press; Layne et al., 2001; Layne et al., 2008; Saltzman et al., 2001).

Evidence 1: Confirmatory Factor Analysis

(Kaplow, Layne, et al., 2018)

PCBD shows evidence of a multi-dimensional structure in bereaved children and adolescents.

- 2-factor model fit data better than a 1-factor model X2(366, N = 367), = 789.67, CFI = .911, Tucker-Lewis Index = .904, RMSEA =- .055 SRMR = .047.
- Standardized estimates of factor loadings were all significant (range = .50-.82).

A first type of evidence is that the PCBD Checklist shows **evidence of factorial validity** based on a CFA analysis contrasting a 2-factor versus 1-factor solution. Namely, PCBD shows evidence of a multifactorial structure in that the 2-factor model yielded significantly better fit than the 1-factor model (Kaplow, Layne, et al., 2018).

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Evidence 2: Functional Impairment

A second type of evidence is that a **PCBD Diagnosis**, as well as **PCBD Criterion C**, are both associated with functional impairment in developmentally salient domains, including family relationships, peer relationships, and school functioning. In contrast, meeting PCBD Criterion B, as well as the Traumatic Bereavement Specifier, were not significantly associated with impaired functioning in any of the three assessed domains—a finding I will return to later (Kaplow, Layne, et al., 2018).

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- Evidence 3: Test Validity
- Good content validity, inter-rater convergence (Content Validity Ratio)
 Discriminant-Groups Validity): Those who met criterion (Dx, Criterion B, Criterion C) had higher posttraumatic stress & depression scale scores.
- Convergent/discriminant validity: youth who met TBS had higher posttraumatic stress, but not depression, scale scores.
- Incremental validity: Criterion C symptom scores (but not Criterion B scores or TBS) predicted 3 types of functional impairment (family, peers, school) after controlling for depressive & posttraumatic stress, age, gender, race/ethnicity.

(Kaplow, Layne, et al., 2018; Layne, Kaplow, & Pynoos, 2014)

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A third type of evidence centers on the **test validity of the PCBD Checklist**. Namely, we have found evidence of (Kaplow, Layne, et al., 2018; Layne, Kaplow, & Pynoos, 2014):

- Good **content validity and inter-rater convergence** (i.e., good Content Validity Ratio values)
- **Discriminant-Groups Validity**): Youth who met PCBD criteria (full diagnosis, Criterion B, Criterion C) had higher posttraumatic stress & depression scale scores than youth who did not.
- **Convergent/discriminant validity**: Youth who met the Traumatic Bereavement Specifier had higher posttraumatic stress, but not depression, scale scores.
- **Incremental validity**: Criterion C symptom scores (but not Criterion B scores or meeting the Traumatic Bereavement Specifier) predicted 3 types of functional impairment (family, peers, school) after controlling for depressive & posttraumatic stress, age, gender, race/ethnicity.

Evidence 4: Children as Reporters

- Kids can self-report on their grief reactions by ages 8-9 under certain conditions (Layne, Kaplow, & Youngstrom, 2017):
- Developmentally appropriate items (translated into kidspeak, going for that uncanny "how did you know that?" look)
- uncanny "how did you know that?" look)

 Importance of unpacking criteria (avoid double-barreled items, ambiguous wording)
- Fleeting, transitory, ephemeral nature of children's emotional states
- Limited vocabularies for expressing emotions
 Limited capacity for reflection, insight
- Youth may do well in one developmental domain and poorly in another

<u>Recommendation</u>: Call attention to need for developmental vetting of symptom criteria wording, relying on collateral sources of information, assessing across repeated time intervals and developmental domains. A fourth type of evidence centers on whether children and adolescents can serve as reliable reporters of their own grief reactions. We found that kids can validly report on their grief reactions by ages 8-9 under certain conditions (Kaplow, Layne, et al., 2012; Layne, Kaplow, & Pynoos, 2014). These conditions include:

- Using developmentally appropriate test items (Kidspeak). It is possible! (Nader & Layne, 2009).
- It is vitally important to unpack grief criteria into simple propositions/thoughts/phrases, rather than loading up a given symptom with multiple elements and meanings. Double-barreled, ambiguous wording makes test construction much more difficult because you have to consider how many different propositions each double-barreled or ambiguous symptom contains, how to word each one in Kidspeak, and then field test and iterate them until they work. Some PCBD diagnostic symptoms in DSM-5 required the development of 2, even 3, separate test items to accurately differentiate and capture (Layne, Kaplow, & Pynoos, 2014). This makes test construction, administration, scoring, and interpretation longer and more complex. It also creates room for ambiguity and uncertainty in clinical diagnosis more generally.
- Children's emotional states are often more fleeting and **ephemeral** than adults (they come and go more quickly).
- Children typically have limited **vocabularies** for expressing emotions
- Children typically have limited capacity for **self-reflection and insight**, such as evaluating how well they have been doing since the death, or considering whether they are undergoing an identity crisis or an existential crisis.
- Youth may do **well** in one developmental domain and **poorly** in another, underscoring the importance of assessing functioning across multiple developmental domains (e.g., school, family, peers) and including multiple informants where possible.
- A long-standing literature (e.g., Nader et al., 1990) documents an interaction with developmental periods. Namely, among young children (< 6 years old), parental bereavement carries a significant risk for developing a separation anxiety disorder, whereas among school-age children and adolescents, parental bereavement is associated with increased risk for co-morbid depression (Pynoos, 1992).

This leads to our second recommendation: Our findings call attention to the need for <u>careful vetting of symptom criteria wording with developmental specialists</u>. More generally, they underscore the value of assessing across repeated time intervals, developmental domains, and information sources such as caregivers who may provide unique information (Kaplow, Layne, & Pynoos, 2019; Layne & Kaplow, in press).

A fifth type of evidence involves **prevalence estimates**. Using data from the first five sites to join the practice research network (N = 367, ages 8-18, used in validating the PCBD Checklist), we found an estimated prevalence rate of 18% (Kaplow, Layne, et al., 2018).

- Put simply, about 1 in 5 youth referred for some type of bereavement-related service (supportive grief services or therapeutic counseling) in the practice research network met provisional diagnostic criteria for PCBD.
- This is a substantial prevalence rate for any disorder. Drawing on principles of evidence-based assessment, this finding underscores the need for two major steps to advance the field (Layne & Kaplow, in press):
 - routine risk screening for grief disorders in both clinical settings and grief support facilities,
 - the creation of risk screening and referral networks for youth who screen positive, so that youth who test positive can receive more in-depth assessment and grief-informed therapeutic services as needed.

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Evidence 5: PCBD Prevalence Rates in Bereaved Youth Referred for Services

N = 367 (PCBD Checklist validation sample):

- PCBD Rates: <u>18%</u> (of youth referred for services offered by practice-research network sites)
- About 1 in 5 youth referred for some type of bereavementrelated service (supportive or therapeutic)

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Developmental Perspectives on Criterion B Symptoms

Separation Anxiety/Distress (pining, yearning, longing for reunion)
Intense emotional pain has three facets:

- Difficulty <u>regulating</u> intense emotional pain (If I start crying I won't be able to stop)
- Deprivation over the loss (not having a father any more, painful feelings of being deprived of his instrumental support in helping me get through things)
 Handling developmental tasks and transitions (menses, dating, career, marriage)
 Feeling deprived or cheated when you see intact families
 Klds: Here and now deprivations; adolescents: future/anticipated deprivations
- · Adolescents: The deceased's own deprivation (all the things they've missed

<u>Recommendation</u>: Do not conflate and combine these two sources of distress (separation distress, deprivation-related distress) into one symptom. Both help to explain the types of distress observed in bereaved youth.

Underscoring the advantages of a multidimensional formulation of grief, our evidence base allows me to comment on three of the PCBD Criterion B hypothesized "Gateway" symptoms presumed to lead to the full complex of symptoms. In particular, bereaved youth tend to endorse both: **Separation Anxiety/Distress** (pining, yearning, longing for reunion); and **Intense emotional pain.** We believe this intense emotional pain has up to three different facets. These include:

- 1. Difficulty regulating intense emotional pain (e.g., "If I start crying I won't be able to stop")
- **2. Deprivation over the loss** (not having a father any more, painful feelings of being deprived of his instrumental support in helping me get through challenging tasks). Examples include:
 - o Handling developmental challenges, tasks, and transitions (menses, dating, career choice, marriage)
 - o Feeling deprived or cheated (e.g., seeing intact families makes me miss how our family used to be)
 - o Kids tend to feel deprived in the here-and now, such as missing them when I get home; adolescents tend to feel deprived both in the present and in an anticipated future (e.g., missing dad at graduation or marriage)
- 3. Adolescents can also empathically consider the deceased's own deprivation—what the death has robbed them of (all the things dad is going to miss as the years pass; e.g., my high school graduation, marriage, babies born)

Let me elaborate further: There is an extensive literature on child bereavement that supports certain features of PCBD's four B Category "gateway" questions. For decades, there has been a balanced perspective in the child bereavement literature regarding **separation distress** (pining, yearning to be reunited, missing the person's physical presence and companionship) evoked by the loss, and sustained emotional pain characterized by a sense of **deprivation** evoked by the loss of a parent, sibling, or close friend. We have seen this in Bosnian youth reports that "life without father gets harder and harder" in terms of the daily adversities, instability, uncertainty, loss of a sense of protection, and other deprivations consequent to the loss of a father (Al-Sabah et al., 2015).

Developmental Perspectives on Criterion B Symptoms

<u>Separation</u> Anxiety/Distress (pining, yearning, longing for reunion) <u>Intense emotional pain</u> has three facets:

- Difficulty <u>regulating</u> intense emotional pain (If I start crying I won't be able to stop)
- Deprivation over the loss (not having a father any more, painful feelings of being deprived of his instrumental support in helping me get through things)
 Handling developmental tasks and transitions (menses, dating, career, marriage)
 Feeling deprived or cheated when you see intact families
 Klds: Here-and now deprivations; adolescents: future/anticipated deprivations
- Adolescents: The deceased's own deprivation (all the things they've missed)

Recommendation: Do not conflate and combine these two sources of distress (separation distress, deprivation-related distress) into one symptom. Both help to explain the types of distress observed in bereaved youth.

Deprivation also appears in the form of **loss of instrumental social support**, such as a young adolescent girl hating it that her mother is not there to help coach her through her first menstruation (Kaplow et al., 2012). This sense of deprivation carries different meanings for children and adolescents over development, as they encounter new developmental tasks, developmental transitions, new challenges, and new opportunities for growth (Layne, Pynoos, & Griffin, 2019). For example, bereaved younger children are often preoccupied with here-and-now questions such as "who will take care of me?" (Layne, Warren, et al., 2009), such as "who will braid my hair?" and "who will get me ready for school?"

In contrast, adolescents are often preoccupied by anticipated deprivations in their future, such as "Who will be there for me to help me decide on a career?" "How will I pay for college?" or "Who will walk me down the aisle when I get married?" We believe this places adolescents at risk for a sense of blighted future we see in bereaved youth struggling with an existential crisis, which can manifest as a relinquishing of positive developmental aspirations or, in severe cases, abandoning a future orientation (Layne et al., 2017; Saltzman et al., 2017).

For example, (Brent et al. 2012) found that parentally bereaved youth reported more work difficulties, less-elaborated career plans, lower peer attachment, and diminished educational aspirations. Thus, **one observation we have** is that the current wording in PCBD is not sufficiently developmentally appropriate to capture how it hurts not to have their parent or close friend there to help and accompany them through a life challenge, developmental transition, or life-enriching opportunity.

<u>This leads to our third recommendation</u>: Do not conflate and combine these two sources of distress (<u>separation</u> distress vs. <u>deprivation</u>-related distress) into one symptom. Both separation distress and deprivation-related distress help to explain the types of distress observed in bereaved youth.

Developmental Perspectives on Criterion B Symptoms

- Distress over the circumstances of the dying and the death carries special developmental importance for children and adolescents (e.g., "The way __died makes it hard to talk about him")
- We have observed these preoccupations in children bereaved by non traumatic deaths (Kaplow, Howell, & Layne, 2014).
- These findings align with early major findings regarding the key role of anxieties surrounding the circumstances of the death in children's maladjustment following parental death (Furman, 1974)

Recommendation: Retain preoccupation with the circumstances of the death as an important clinical manifestation and clinical focus in bereaved youth

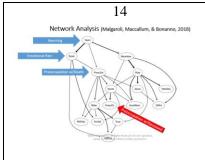
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Speaking of a third Criterion B (hypothesized "gateway") symptom, the child and adolescent bereavement field has for years found that <u>distress over the circumstances of a death</u> is a major dimension of children's' reactions to loss by death. This should not be construed as simply PTSD. Using a multidimensional theory of grief (Layne et al., 2017), **anticipated** deaths- not only traumatic deaths—clearly carry a significant risk of sustained distress over the particular manner of death and its surrounding circumstances, including distress linked to the course of an illness and to the process of dying. This was empirically demonstrated in one of our studies (Kaplow, Howell, & Layne, 2014). Circumstance-related distress can stem from watching a parent or sibling deteriorate over the course of a slow wasting illness; witnessing the intense distress of other family members or caregivers; feeling regret or remorse over being on bad terms before the person's death; distress over a senseless, degrading, or tragic death—"he deserved better than that"; perceptions that the deceased did not receive good medical care, and perceptions that the death was preventable.

We have observed school-age children struggle with loss reminders (including a **wish** to avoid loss reminders, even when they are not allowed to do so), which can renew distress over the process of dying or death (Howell et al., 2014; Layne et al., 2006). In contrast, we are observing that adolescents are more likely to experience deep empathic sorrow over the degree of suffering, including whether a parent, sibling, or friend died alone, was afraid or in pain, or had comforting companionship in their last moments. This preoccupation with *how* a loved one died, regardless of whether the death can be classified as traumatic or non-traumatic, has emerged as an important focus for intervention with bereaved youth (Saltzman et al., 2017).

Indeed, a core proposition of multidimensional grief theory is that Separation Distress and Existential/Identity-related distress emanate from the fact **that** the loved one died, regardless of the manner of death. It does not take a terrible death to miss them terribly or experience a loss of personal identity or an existential crisis. In contrast, circumstance-related distress emanates from **how** the loved one died—its tragic and perhaps traumatic nature (Layne et al., 2017). These core propositions carry direct implications for unpacking the pathways of influence that link specific risk factors to specific types of grief and other distress reactions (e.g., Layne et al., 2010). Namely, the theory hypothesizes that **difficult deaths increase risk for Circumstance-Related Distress; whereas the centrality of one's relationship to the deceased in your life, a high degree of dependency/interdependency, and severe deprivations and hardships increase risk for Separation Distress and Existential/Identity Distress** (Layne et al., 2014). These propositions shed light on why we named it "multidimensional grief theory" rather than "traumatic grief theory," given that the latter emphasizes only traumatic death as a risk factor, circumstance-related distress and PTSD as outcomes, and traumatically bereaved youth as an at-risk group.

These findings also align with those from the earliest longitudinal studies of parentally bereaved children (now 45 years old) in underscoring the clinical value of **preoccupation with the circumstances of the death itself, and not simply the person who died**, as in important focus of treatment. We thus recommend retaining preoccupation with the circumstances of the death as an important clinical manifestation and clinical focus in bereaved youth. As described in Erna Furman's (1974) early work, "It sometimes appeared that a child had difficulty in mourning; closer study revealed that the child's difficulty lay primarily in coping with anxieties about the circumstances surrounding the death, which the child's mind could not master and his environment failed to allay."



Developmental Perspective on Criterion C Symptoms Kaplow, Layne, Pynoos, Cohen, & Lieberman (2012)

- Children often cannot avoid reminders (but wish they could)
- Children depend heavily on caregivers to facilitate healthy and adaptive grieving (remembering, reminiscing)
- Developing Grief Facilitation Index (Kaplow & Layne, 2014)

<u>Recommendation</u>: Avoidance of reminders should be developmentally modified to reflect a <u>wish</u> in children to avoid reminders of the deceased, even if children are unable to do so in their behavior.

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Developmental Perspective on Criterion C Symptoms
Hill, Kaplow, Oosterhoff & Lavne (2019)

Social Identity Disruptions in Maladaptive Grieving

- Critical role of Identity/social disruptions in bereaved older children, adolescents who struggle with fitting in and belonging.
- Carries risk of feeling different from their peers during a critical
- developmental period and developmental task (social integration).
- Criterion C symptoms predict thwarted belongingness, an established risk factor for suicide ideation/behavior in youth (Hill et al., 2019).

<u>Recommendation</u>: Social identity/disruption questions should be <u>unpacked and posed as simple single questions</u>. If necessary, this should be done at the expense of dropping other less-specific items that may reflect multiple causes (e.g., inability to trust others).

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The value of drawing this distinction between **preoccupation with the death, versus preoccupation with the deceased**, is also underscored in the adult literature. In a naturalistic longitudinal study of bereaved adults Malgoroli, Maccalum, & Bonnano (2018) performed a network analysis at 3 months, 14 months, and 25 months post-death. At all points, preoccupation with circumstances related to the death was an early and primary pathway that activated a major set of Criterion C symptoms, including feeling alone, bitterness, maladaptive appraisals, and avoidance of reminders. This is consistent with its hypothesized "B symptom" role as an active gateway and primary conduit to the full constellation of symptoms. In contrast, **preoccupation with the deceased** occupied a downstream "dead end" role in the model that did not predict the activation of any subsequent symptoms.

This leads to our fourth recommendation: Preoccupation with the death and preoccupation with the deceased are not functionally interchangeable. Based on these convergent sources of evidence, we urge that these two types of distressing preoccupation be kept distinct and not conflated by combining them into one symptom, and that both types of distress be represented in the new grief diagnosis.

Let me turn my attention to PCBD Criterion C symptoms. There are important developmental implications for avoidance of reminders, in that children often cannot avoid reminders that adults place in their way, such as a boy who came home and was confronted daily with lit candles and pictures of his deceased father in their front walkway. Children rely on parents and caregivers to facilitate their grieving and mourning (e.g., a girl cannot visit her father's grave unless her mother drives her; children rely on caregivers to help them talk about, remember, reminisce about, learn more about, and identify with, their deceased loved one) (Howell, Shapiro, Layne, & Kaplow, 2014; Howell et al., 2016). Similarly, children may also be confronted involuntarily with reminders they wish to avoid, such as a caregiver's choice to display a memento that the child perceives as a trauma or loss reminder.

<u>This leads to our fifth recommendation</u>: Avoidance of reminders should be developmentally modified to reflect a <u>wish</u> in children to avoid reminders of the deceased, even if children are unable to do so in their behavior (Kaplow et al., 2012).

We also wish to emphasize the critical role of social/identity disruptions and the existential challenges they pose. To date, our practice-research network data reveal higher rates of endorsement of social/identity disruption among adolescents. We propose that identity/social disruptions are a key clinical issue for bereaved older children and adolescents who struggle with feelings of being different from their peers during a critical developmental period and critical developmental tasks (i.e., identity formation, social integration). These perceptions of being different, isolated, or rejected can exacerbate the loneliness and deprivation that accompanies loss and increase suicide risk (Hill et al., 2019).

We have treatment outcome evidence from three different data sets, including post-war Bosnia (Layne et al., 2001; 2008), high-risk youth in Delaware (Grassetti et al., 2014), and the TAG Center in Houston (Hill et al., in press), that **social/identity disruption in adolescents** is a common clinical concern among bereaved adolescents. Further, we have evidence from two outcome studies that therapeutically addressing social/identity disruption is associated with reductions in maladaptive grieving, as well as improvements in classroom behavior, school performance, and motivation for learning (Layne et al., 2001; Layne et al., 2008).

These findings lead to our sixth recommendation: Social identity/disruption questions should be unpacked and posed as simple single questions to avoid double-barreled wording. If needed to enhance parsimony, this should be done at the expense of dropping other less-specific grief items that may reflect multiple causes (e.g., an inability to trust others).

Our findings converge with adult findings regarding identity disruptions, existential crises (Malgaroli et al., 2018)

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Developmental Perspective on Criterion C Symptoms

Our findings also converge with those of adult studies. Referring again to the network analysis by Malgaroli et al. (2018), **role confusion and meaninglessness (right side of the model)** are particularly central in their model and predict subsequent pathology including loneliness, wishing to join the deceased in an afterlife, difficulties in pursuing interests, and difficulty trusting.

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Network Analysis (Malgaroli, Maccallum, & Bonanno, 2018)

Malgaroli et al observe: (p. 2445, bolding added)

"Overall, these findings suggest that role confusion, meaninglessness, and loneliness carry a greater role in grief pathology than currently expressed by the PCBD criteria. In fact, a PCBD diagnosis is currently possible without endorsing any symptoms related to social/identity disruptions."

These findings raise the question: Should a social/identity item be required, rather than optional, to meet diagnostic criteria?

Malgaroli et al. conclude (p. 2445) that "Overall, these findings suggest that **role confusion, meaninglessness**, and **loneliness** carry a greater role in grief pathology than currently expressed by the PCBD criteria. In fact, **a PCBD** diagnosis is currently possible without endorsing any of symptoms related to social/identity disruptions."

<u>These findings raise the question</u>: Should an existential/identity item be required, rather than optional, to meet diagnostic criteria?

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Developmental Perspective on Criterion C Symptoms

Desire to die to be reunited with the deceased and risk for suicide ideation & behavior

- Reunion fantasies among younger children can take the form of a need or desire to literally die in order to rejoin the deceased (M endorsement = 2.25 on a 0-4 point frequency scale)
- · Fantasies of dying to be reunited with the deceased increase suicide risk
- Both thwarted belongingness, and a desire to die to be reunited with the deceased, can contribute to increased lifetime risk for suicide for parentally-bereaved youth.

<u>Recommendation</u>: A desire to be reunited with the deceased should be retained in any revision of Criterion C symptoms.

COURT OF Pagards, All Pigits Reserved, Discout reprodquate, or distribute without written permission. Also of developmental concern is the **relation between a desire to die in order to be with the deceased and suicide ideation**. There is a well-established link between bereavement and suicidal ideation in adolescents. More recently, a population-based cohort study from three Scandinavian countries documented an increased long-term risk of suicide associated with parental death in childhood, regardless of the cause of death. PCBD criteria are providing a useful tool with which to re-examine this critical issue. In a recently published study of bereaved adolescents (Hill et al., 2019), PCBD Criterion C scores significantly predicted **thwarted belongingness**, a well-established proximal risk factor for suicidal ideation in youth. Indeed, every 1-point increase in Criterion C scores was associated with an estimated 0.30 increase in suicide ideation on the scale used.

Further, reunion fantasies among younger children can take the form of a literal need to die to rejoin the deceased (Kaplow et al., 2012). Our practice research network data reveal that even younger children (aged 8-9) endorse the item "I imagine or daydream about dying so that I could be with again" with regularity. This finding is of even greater clinical concern when one observes children bereaved by parental suicide wondering aloud and playing at how many pills they would have to take to die and join their parent who took their life.

These findings lead to our seventh recommendation: A desire to be reunited with the deceased should be retained in any revision of Criterion C symptoms.

On the Empirical Distinctiveness of Grief, PTSD, and Depression

- Unpacking large-scale catastrophes (school shootings, terrorist attacks) into constituent risk factors for:
 PTSD (dose of exposure/proximity to harm, physical injury, danger, fear for others
- Grief (degree of acquaintance/psychological proximity to those killed)
- Grief (degree of acquaintance/psychological proximity to those killed)
- Elementary School Shooting (Pynoos et al., 1987; Nader & Pynoos, 1990)
- Virginia Tech Shooting (Smith, Layne, et al., 2017)
- Virginia lech Shooting (Smith, Layne, et al., 2017)
 September 11th Attack (Geronazzo, Fan, Duarte, Layne et al., 2019)
- Inventories of Trauma Reminders and Loss Reminders as separate mediators of long-term adjustment.

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Let me now turn to available evidence regarding the **empirical distinctiveness of grief from PTSD and depression, which are often co-occurring conditions.** As I noted earlier, our confirmatory factor analysis model results supported a 2-factor solution over a 1-factor solution, suggesting that PCBD B and C Category symptoms are meaningfully distinct from one another. This is consistent with a multidimensional conception of grief reactions.

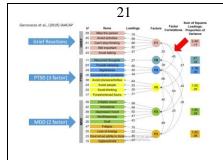
Evidence regarding the distinctiveness of grief from PTSD and depression comes from a line of research that is more specific to the child and adolescent traumatic bereavement literature. For several decades, the child bereavement field has been examining both the independence of, and interplay between, grief reactions, posttraumatic stress reactions, and depressive symptoms (Layne et al., 2017; Nader, 2020; Pynoos et al., 1987). The child and adolescent field has adopted a somewhat different research strategy than most adult studies by investigating the onset and course of grief, PTSD, and depression in response to large-scale catastrophic violent events, such as school shootings. Again, the strategy derives from the concept of differential relations and its utility for "unpacking" and distinguishing between related but meaningfully distinct constructs that I described earlier (Layne et al., 2010; Layne et al., 2014). Namely, a selected number of child and adolescent field studies test the predictive effects of three different risk factors (external criterion variables) theorized to differentially contribute to PTSD, grief, and depression (three different outcomes):

- (a) a physical proximity (dose of exposure) model hypothesized to increase risk for PTSD,
- (b) a psychological proximity (degree of acquaintance) model hypothesized to increase risk for grief,
- (c) cascading secondary adversities (ensuing hardships) hypothesized to increase risk for depression.

Examples of these study designs include a one-year follow-up study of a sniper attack on an elementary school playground in the 1980's (Nader, Pynoos, Fairbanks, & Frederick, 1990), the New York Board of Education city-wide risk screening after 911 (Geronazzo-Alman et al., 2019), and a longitudinal study of students exposed to the Virginia Tech shooting (Smith et al., 2017). These study designs permit examination of the differential effects of trauma, bereavement, and secondary adversities. For example, in the elementary school shooting, some children underwent direct life threat but did not know the murdered or wounded children; other children knew the deceased well but were not under any life threat; and others underwent both life threat and knew the deceased well. **Underscoring the distinctiveness between PTSD and grief reactions, differential effects emerged.** Physical proximity to the shooting strongly predicted PTSD, psychological proximity to the deceased strongly predicted grief, and the co-occurrence of PTSD with grief was associated with a more prolonged and severe course of both sets of reactions. Children with co-occurring PTSD and grief reactions were at increased risk for severe persisting grief reactions **and** PTSD symptoms and manifested a complex interplay in which each set of reactions exacerbated the other (Nader et al., 1990; Pynoos, 1992). These findings were largely replicated in our study of college students at Virginia Tech (Smith et al., 2017): closeness to the deceased predicted grief reactions one year later regardless of degree of exposure.

Further underscoring the empirical distinctiveness of grief versus PTSD, only 9% of bereaved children met criteria for both PTSD and PCBD in our practice-research network data, showing a low rate of diagnostic comorbidity (Kaplow et al., 2018). Underscoring the distinctiveness of circumstance-related distress (grief reactions) from PTSD symptoms, many youth in the sample reported high levels of circumstance-related distress (e.g., shame, guilt, remorse) in relation to the deceased and to the death, but did not report high levels of PTSD.

These findings lead to our eighth recommendation: Many bereaved youth experience clinically significant distress linked to the circumstances of the death of a loved one that cannot be accurately attributed to PTSD. Rather, the forthcoming grief disorder should acknowledge ways in which disturbing, tragic, and traumatic aspects of deaths can influence the clinical origin, manifestations, and clinical course of grief reactions over time, while also potentially increasing the risk for PTSD and related stress-related conditions.



Let me illustrate this approach in our recently-published 9/11 study (Geronazzo-Allman et al., 2019). Because data collection preceded DSM-5 by years, we were examining the basic distinction between adaptive versus maladaptive grief items and not PCBD. Note the weak to moderate inter-factor correlations among the three disorders, suggesting they are moderately related but meaningfully distinct. The differentiated model yielded acceptable fit. From a developmental vantage-point, traumatically bereaved children and adolescent are taxed by the demands of coping with posttraumatic stress, grief, and depressive reactions, each of which may call for different types of caregiving support and therapeutic intervention (Saltzman et al., 2017).

Returning to the concept of differential relations, a key distinction between grief and PTSD centers on differential relations between trauma reminders (e.g., of the disturbing circumstances of the death) and loss reminders (e.g., their name, picture, belongings), and posttraumatic stress reactions and grief reactions. Our team has developed inventories for assessing frequencies of exposures to, differences in coping with, and degree of impairment caused by, trauma reminders versus loss reminders (Layne, Djapo, & Pynoos, 2010; Layne, Savjak, & Steinberg, 1999). In a study of war-exposed Bosnian youth, we found that exposure to loss reminders strongly predicted grief reactions, whereas exposure to trauma reminders strongly predicted posttraumatic stress reactions, and that different coping strategies differentially related to different reminders. Although secondary control coping proved useful for both trauma and loss reminders, disengagement towards trauma reminders was associated with an exacerbation of PTSD symptoms (Howell, Kaplow, et al., 2014). These differential relations among theorized mediators (trauma reminders, loss reminders, and coping strategies) again underscore the distinctiveness between PTSD and grief (Layne, Kaplow, Netland, et al., 2014).

Let me address an additional topic relating to key distinctions between grief and mourning. Our work to date, both at the national and international levels, underscores the need to **re-introduce mourning and mourning rituals**, **not simply grief reactions**, into the consideration of a bereavement disorder. Culture carries important developmental considerations. These include whether children and adolescents are expected or allowed to **participate in some mourning rituals** (e.g., funerals), which can have a measurable impact on subsequent adjustment. Culture can also influence whether and how caregivers facilitate specific types of grief reactions on the basis of whether they are considered to be desirable or undesirable (Howell et al., 2016; Roley-Roberts et al., 2018; Wardecker et al., 2017;). There are also important **cultural prohibitions and prescriptions** (such as forbidding the speaking the name of the deceased, or forbidding crying) that should be taken into account, as these can affect the course of adjustment. Culture can also influence expectations about what constitutes a normal course of grieving, including which adjustment trajectories following the death are considered normal and adaptive (Layne & Hobfoll, 2020). It is also important to acknowledge **societal changes in mourning rituals that have taken place** over time (e.g., candlelight vigils, mourning sites on Facebook, memorial ceremonies at schools), as well as **societal expectations regarding widowhood** that can influence child outcomes (25-year outcomes worse for Armenian children who lost fathers).

This leads to our ninth recommendation: The proposed criteria should acknowledge the role that culture may play in grieving and mourning, and that caregivers often influence whether and how bereaved children participate in mourning rituals. This includes both participation in culturally-linked mourning activities in which children wish to participate (e.g., visiting dad's grave, attending memorials, reminiscing about dad) as well as being constrained to participate in activities that children wish to avoid (e.g., candles and pictures in your home's entranceway; seeing dad's ashes on the mantelpiece; Kaplow et al., 2012).

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Developmental Considerations Regarding Culture

- Need to re-introduce mourning and mourning rituals, not simply grief reactions, into the consideration of a bereavement disorder.
- Important developmental considerations regarding culture.
- Participation in some mourning rituals (e.g., funerals) can have measurable impact on subsequent adjustment,
- Cultural prohibitions and prescriptions (forbid speaking the name of the deceased crying) that should be taken into account, can affect the course of adjustment.

 Cultural expectations regarding the course of grieving.
- Acknowledge societal changes in mourning rituals over time (candlelight
- vigils, mourning sites on Facebook, memorial ceremonies at schools).

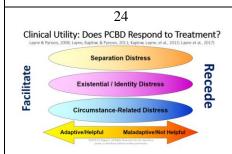
 Societal expectations regarding widowhood also influence child outcome:
- Societal expectations regarding widowhood also influence child outcom (25-year outcomes worse for Armenian children who lost fathers)

Harm/Benefit

Special considerations regarding harm/benefit in school districts.

- Houston Independent School District: 200 bereavementrelated referrals per month in a school district comprised of 288 schools.
- A more pressing institutional problem (overall frequency, lack of local capacity and adequate technology to address it) than frauma

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With respect to harm versus benefit, this question takes on a different calculus when discussing bereavement in children and adolescents. Whereas there continues to be concern about "overpathologizing" adult grief reactions, we are finding a different response in our work in large school districts in regard to children. Our colleague, Dr. Kaplow, is working within the Houston Independent School District, which consists of 288 schools. The school district administrators have actively pursued a working relationship with her program at the Baylor College of Medicine/Texas Children's Hospital because they perceived bereavement to be a more widespread and serious problem for them than trauma, with an estimated 200 deaths of immediate family members per month districtwide, with substantial impact on school attendance, school performance, and behavior. They are working towards the goal of building district-wide capacity to identify, assess, and treat those with PCBD, including adopting measures of school functioning and positive youth development.

We thus propose that there are greater risks associated with not identifying and treating bereaved children who need it. Risks that unidentified bereaved youth may incur include being labelled deviant for their behavior, losing motivation for learning, low or failing grades, receiving no tutoring support, and social isolation. Indeed, a nationally representative study of adolescents (Oosterhoff, Kaplow, & Layne, 2018) found that bereavement due to sudden loss (exposure to sudden loss *per se*; grief reactions were not measured) was inversely associated with each of the six indicators of academic impairment included in the survey, including feeling like teachers don't understand you.

Last, a major factor when considering a new diagnosis is its **clinical utility**. PCBD has shown itself to demarcate a group of bereaved children who exhibit multiple types of significant distress and impaired functioning (Kaplow et al., 2012). A distinct advantage of multidimensional grief theory is that it prescribes practice elements that actively facilitate adaptive grief responses on one hand, paired with practice elements designed to help maladaptive grief reactions to recede on the other (Saltzman et., Introduction to Module 3). This multidimensional approach allows clinicians to tailor their intervention according to each child's individual grief profile (Module 3), and co-morbid features such as depression (Module 1), PTSD (Module 2), risky behavior (Modules 1-4), and developmental disruption (Module 4). Multidimensional grief theory is conducive to integrating grief-related support facilities (which focus on the **left** side of the model by facilitating adaptive grieving processes); with therapeutic treatment facilities (which focus on **both** sides of the model by helping maladaptive grief reactions to recede while facilitating adaptive grief reactions) (Layne et al., 2017). This can thus support an integrated system of care, including a risk screening and referral network that can provide many bereaved youth with general support while identifying and providing at-risk youth with specialized therapeutic services (Layne & Kaplow, in press).

As noted in our ninth recommendation, working with school age and younger children requires understanding that **children depend heavily on their immediate caregiving environment to help facilitate their mourning** (Howell et al., 2015; 2016; Roley-Roberts et al., 2018; Wardecker et al., 2017). Strengthening the caregiving system includes helping caregivers to recognize the child's wish to grieve, help the child disclose details of the death, answer questions in developmentally appropriate ways, provide support when confronting loss reminders, and finding ways to compensate for loss-related deprivations (Kaplow, Layne, & Pynoos, 2014; Kaplow et al., 2013; Saltzman et al., 2011; 2013; 2017).

Separation Distress (Avoidance of Loss Reminders)



26 Circumstance-Related Distress (Shame Over Stigmatized Death)



Staying on the topic of **clinical utility**, let me give some brief examples of our dual emphasis on helping less adaptive grief reactions to recede while facilitating adaptive reactions (Layne, 2018). These exercises illustrate both the clinical utility of multidimensional grief theory and of our modularized, flexible approach that allows practitioners to tailor therapeutic exercises according to which grief subscales are elevated in youths' assessment profiles. One example of a practice element from our treatment manual for bereaved and traumatically bereaved adolescents (Saltzman et al., 2017) involves sketch-based exercises that focus explicitly on potential ways in which youth may have difficulties coping with a particular grief-related challenge. A central challenge for **Separation Distress** is "How can I continue to feel connected to the person who died, so that they remain an important part of my life?" (Layne et al., 2017). For example, a sketch depicts a youth whose dad died wants to avoid going to a ball game because it is what he and his dad used to do together. That is, he wishes to avoid a loss reminder. The practitioner tailors intervention by selecting sketches that depict grief-related challenges specific to the elevated grief domain(s) and holding therapeutic discussions. Especially in adolescents, over-identification with unhealthy parts of the life and behavior of a deceased parent, sibling or friend can be conceptualized as an unhealthy effort to reduce separation distress. Our model prescribes a variety of different practice elements to address unhealthy separation-related reactions, including remembering and reminiscing exercises focusing on positive attributes that (a) help the adolescent feel close to them and (b) they can carry into the future by incorporating into their identities, values, and aspirations (Layne et al., 2017).

However, we also recognize that this practice element can be problematic if the deceased's behavior was abusive. Thus, we also have exercises that allow youth to both acknowledge the person's faults, identify their admirable qualities, and decide which they wish to identify with and bring into their future (Saltzman et al., 2017-see Module 3).

We also address circumstance-related distress through practice elements that focus on remembrances about the dying, including regrets over dying alone, concerns over it taking so long, over physical changes to the body, vexing concerns over the degree of suffering, and unanswered questions they would like clarified for their own sake (Pynoos, 1992). In cases where there is **co-morbid PTSD**, there is preceding active work over reducing sensory-embedded intrusive imagery (Saltzman et al., 2017, Module 2). The **adaptive side is to explore with the child how they might like to make their life a constructive response to the way they died** (Modules 3 and 4). Notably, adults engage in such constructive activities as this all the time in establishing or participating in charities that are looking to conquer certain diseases, in career choices, and in their interpersonal and moral values. Therapeutic involvement of bereaved children and adolescents in these efforts can be a constructive response to distress over the circumstances of the death.

Finding comforting ways to memorialize the deceased are common practice elements in many grief-focused interventions. In contrast, a focus on explicitly recognizing the circumstances of the death, and therapeutically leveraging bereaved youths' often-potent and poignant reactions to them in constructive ways, is less common, yet a potentially very powerful therapeutic intervention (Layne et al., 2017). Building this into our treatment, we have found that it can galvanize group cohesion (Davies, Burlingame, & Layne, 2006; Grassetti et al., 2014), enhance supportive exchanges between members (Layne, Pynoos, & Cardenas, 2001), mobilize altruistic and prosocial activities that help others in need and improve their communities (Oosterhoff, Kaplow, Layne, & Pynoos, 2018), and motivate youths to change the course of their lives for the better, such as through career choices or embracing positive values (Cox et al., 2007; Saltzman et al., Modules 3 & 4).

Existential Distress (Abandonment of Life Aspirations)



We also address **existential/identity distress** using exercises that help bridge a sense of historical discontinuity and disrupted identity in adolescents by creating bridges between *who I was before the death, versus who I am today*. If an existential crisis is present, we gently challenge their perception that their future prospects are irreparably damaged and blighted as a result of the death, and include exercises to help them form healthy future aspirations (Saltzman et al., Modules 3 & 4). In group settings, we harness the power of the group to build a sense of cohesion and solidarity, facilitate comforting social comparisons, create an affirming forum for self-disclosure, and practice support-exchanging skills (Davies et al., 2006; Layne, Pynoos, & Cardenas, 2001).

28

Clinical Utility: Does PCBD Respond to Treatment?

Hill et al., (in press) open trial (N = 42)

- Analyses of grief reactions consistent with multidimensional grief theory identified significant reductions and very large associated effect sizes in each of the three maladaptive grief domains.
- Separation Distress, (t(41) = 8.74, p < .001, Cohen's d = 1.35;
- Existential/identity distress, (t(41) = 6.76, p < .001, d = 1.04;
- Circumstance-related distress, (t(41) =7.58, p < .001, d = 1.17.
- Over 60% reliably improved on at least one grief subscale after the first phase of treatment as gauged using the Reliable Change index. Of more seriously distressed youth, 80% reliably improved from baseline to the end of Phase 2 on all grief-related outcomes.
- Almost no reliable deteriorators (iatrogenic effects).

29

Additional Clinical Considerations

As we accumulate data through this network, we have early evidence of two important subgroups who will require special attention:

- Supgroup who have a <u>primary diagnosis of PTSD</u> post-death without PCBD.
- Subgroup who have a <u>primary diagnosis of depression</u> without PCBD (David Brent and colleagues have contributed to this body of work).

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Let me summarize the results of a recent open trial (Hill et al.., in press) utilizing this multidimensional approach to conceptualizing and treating grief. The trial is of outcomes associated with Multidimensional Grief Therapy (Kaplow, Layne, Pynoos, & Saltzman, under contract), a treatment for bereaved children and adolescents (not adolescents only) currently in development led by Dr. Kaplow. Multidimensional Grief Therapy is based on multidimensional grief theory and adapted from Trauma and Grief Component Therapy for Adolescents. We used the Reliable Change Index to assess treatment response across the three primary grief dimensions at an individual-case level. The Reliable Change Index classifies clients according whether they have significantly improved (Reliable Improvers), significantly worsened (Reliable Deteriorators), or not significantly changed (Treatment Nonresponders). It is especially important to search for reliable deteriorators when evaluating new disorders and new treatments. Our results indicate that over 60% of youth reliably improved on at least one grief dimension, most on multiple dimensions, during the first phase of a grief-focused intervention with almost no reliable deteriorators (which would suggest an iatrogenic effect).

With regard to additional clinical considerations, as we accumulate data through this network, we have early evidence of two important subgroups that require special attention:

- A subgroup of youth who have a **primary diagnosis of PTSD post-death without PCBD**.
- A subgroup of youth who have a **primary diagnosis of depression without PCBD** (David Brent and his colleagues have contributed to this body of work).

The presence of these subgroups underscores the value of not only assembling risk screening batteries that are capable of detecting them (Layne & Kaplow, in press), but also of modularized, flexible treatments that can address multiple problem areas.

Summary of Developmental Recommendations

- A Multidimensional framework allows for a more differentiated clinical profile and better support for assessment, training, case treatment planning, and monitoring outcomes.
- PCBD is a reasonably softerent disorder in bereased youth that shows good content validity, growing evidence of convergent/discrimina validity, and good factional validity. As presently constituted, PCBD offers sufficient coverage of the observed clinical profiles of beroaved.
- youth who fall in the clinical range of severe persistent distress and impairment in functioning and behavior.

 3. PCRD is also showing address of distract at the production residue residue residue residues to multidimensional assessment of them, modularized or showing and persistence of distract at the production of the production of
- 4. The Category B Items appear to be working well with youth. Separation distress, interse emotional pain or sorrow, and distress over the drawstance of the death are district in the prominent presenting symptoms and should be retained as gateous forms because they serve a market in this hole-lage distinct of a president between the colored as district. As no explicit children to destrict, a hole broad.
- added that children may express their emotional pain in terms of a daily sense of deprivation over being without a parent, sibling, frience.

 5. Findings that C Category items carry the weight of predicting functional impairment underscores their importance for children and
- Social/liferally disruption items are levy items for children and adolescents that are briked to development, functional impairment, an eterm succion risk consideration should be given to expanding upon, more fully articulating, and possibly requiring changes in identity a personal existential crises as core symptoms.
- 7. For children, it is important to avoid "double-barrel" items, especially if they combine or conflate different concepts. For children and
- 8. It is helpful for children to adopt an adaptive/meladaptive framework, including the importance of caregiver facilitation of adaptive grievi
- 10. Additional risks, challengers, and special features including the course of recovery for those facing traumatic bereavement should be emphasized, either in the traumatic Bereavement Specifier or in the text.
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To summarize, we offer 12 developmental recommendations and 7 general observations for grief disorder criteria.

Developmental recommendations include:

- 1. A multidimensional conceptual framework allows for a more differentiated clinical profile, a balanced strength-based approach, and better support for assessment, training, case formulation, treatment planning, and monitoring outcomes.
- 2. Grief criteria should be carefully vetted with developmental specialists to enhance developmental sensitivity and the accuracy and validity of diagnostic assessment.
- 3. Do not conflate and combine **separation distress** and **deprivation-related distress** into one symptom. These are related but meaningfully distinct reactions that help to explain the range of distress reactions observed in bereaved youth.
- 4. **Preoccupation with the death** and **preoccupation with the deceased** should be kept separate and not conflated by combining them into one symptom.
- 5. Avoidance of reminders should be developmentally modified to reflect a **wish** in children to avoid reminders of the deceased, even if children are unable to do so in their behavior.
- 6. Social identity and disruption questions should be unpacked and posed as simple symptoms to avoid double-barreled wording.
- 7. A **desire to be reunited with the deceased** should be retained in any revision of Criterion C symptoms.
- 8. There should be an acknowledgement of ways in which **disturbing**, **tragic**, **and traumatic aspects of deaths** can influence the clinical origin, manifestations, and clinical course of grief reactions over time.
- 9. Attention should be given to **culture and mourning rituals**, including a recognition that they may influence the manifestations, course, meanings, and receptivity given to grief reactions.
- 10. The proposed grief criteria should acknowledge that **caregivers** often heavily influence whether and how bereaved children participate in mourning rituals.
- 11. "**Double-barreled" items**, especially those that combine or conflate different concepts or symptoms, are problematic. They make the process of assessing bereaved children longer, more complicated, and more prone to error and ambiguity.
- 12. Additional risks, challenges, and special features including the course of recovery for those facing **traumatic bereavement** should be emphasized, either in the Traumatic Bereavement Specifier or in the text.

General observations include:

- 1. PCBD is a **reasonably coherent disorder** in bereaved youth that shows good content validity, growing evidence of convergent/ discriminant validity, and good factorial validity. As presently constituted, PCBD offers sufficient coverage of the observed clinical profiles of bereaved youth who fall in the clinical range of severe persistent distress and impairment in functioning and behavior.
- 2. PCBD is also showing evidence of **clinical utility**, including positive response to multidimensional, assessment-driven, modularized or phased interventions with good rates of reliable improvement and very few or no iatrogenic outcomes.
- 3. PCBD Category B "gateway" items appear to be working well with youth. Separation distress, intense emotional pain or sorrow, and distress over the circumstance of the death are often the prominent presenting symptoms.

They should be retained because they serve as markers in school-age children of persistent bereavement-related
distress that are easy for children to identify and endorse.
a. A note should be added that children may express their emotional pain in terms of a daily sense of
deprivation over being without a parent, sibling, friend, etc.
4. Findings that PCBD Category C items carry the weight of predicting functional impairment underscores their
importance for children and adolescents.
5. Social/identity disruption items are key items for children and adolescents that are linked to development,
functional impairment, and long-term suicide risk.
a. Consideration should be given to expanding upon, more fully articulating, and possibly requiring
changes in identity and personal existential crises as core symptoms.

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