Bereavement, Prolonged Grief Disorder, and Bereavement-Informed Care for Children and Adolescents

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Bereavement due to sudden loss is one of the most common—and most difficult—life events experienced across the life course (Kaplow & Layne, 2014).

Overview

- Grief consists of voluntary and involuntary emotional, cognitive, physiological, spiritual, and behavioral reactions to bereavement (the loss of a loved one to death) *(Layne, 2021)*.
- Adolescents and young adults are at heightened risk for bereavement under traumatic circumstances due to high prevalence rates of accidental and violent death, combined with developmental features including large social networks, sensation-seeking, and risky behavior *(Layne et al., 2017)*.
- Current epidemics, including those stemming from COVID-19, opioid, and suicide are inflicting devastating consequences on youth. COVID-19 orphanhood and caregiver death has bereaved an estimated 10.5 million children worldwide.
    - Caregiver loss can lead to devastating consequences including institutionalization, abuse, grief, mental health problems, adolescent pregnancy, poor educational outcomes, and chronic and infectious diseases *(Hillis et al., 2022)*.
- Bereavement and grief are linked to many adverse outcomes including increased risk for mental health conditions, suicide ideation, school problems, and reduced likelihood of completing each year of school through university (*reviewed in Layne & Kaplow, 2020*).

Wide range of reactions. *Bereaved youth can exhibit a wide range of grief reactions that can in some ways resemble adult grief reactions, with important exceptions* (Kaplow, Layne, Pynoos, Cohen, & Liberman, 2012; Layne et al., 2019, Layne et al., 2020).

- Adaptive grief reactions can include comforting reminiscing, finding a sense of purpose, and constructive responses to the way the person died (e.g., advocacy, service, career aspirations) *(Layne et al., 2017)*.
- Maladaptive grief reactions can manifest in various forms. These include *(Layne, 2021; Layne et al. 2017)*:
    - Severe persisting distress (e.g., intense pining, yearning, and longing)
    - Intense mental preoccupation with the loved one (e.g., can't stop thinking about them)
    - Intense mental preoccupation with how they died (e.g., its traumatic or tragic circumstances)
    - Inability to form comforting connections to the deceased (e.g., impaired reminiscing)
    - Existential crises (e.g., losing the will to live, loss of future aspirations, nihilism)
    - Identity crises (e.g., feeling like the best part of you died with them)
    - Intense distress upon exposure to loss reminders (reminders of their ongoing physical absence) or trauma reminders (reminders of how they died) *(Layne et al., 2006)*.
    - Functional impairment in developmentally important life domains (e.g., school; relationships with family, peers, romantic partners), and especially in youth, developmental disruption (e.g., markedly lower school grades, repeating a grade) or in more serious cases, developmental derailment (e.g., school dropout; entry into the juvenile justice system).

- Adaptive and maladaptive grief reactions co-occur to varying degrees. One method for identifying maladaptive grief reactions centers on evaluating their differentially stronger relations with certain types of external factors *(Layne Kaplow, Netland, Steinberg, & Pynoos, 2014)*. These external factors include *(Layne & Kaplow, 2020; Layne et al., 2006)*:
  - Causal risk factors (e.g., maladaptive grief reactions are more likely to arise in relation to traumatic or tragic and deeply disturbing deaths)
  - Secondary adversities (i.e., major life adversities caused or exacerbated by the death).
  - Functional impairment (e.g., school, relationship problems)
  - Risky behavior (e.g., suicide ideation, substance use, other self-harm/risk-taking behaviors)
  - Developmental disruption (e.g., avoidance of age-appropriate developmental tasks).
  - Trauma reminders (distressing reminders of the traumatic/tragic way in which they died)

Prolonged grief disorder. *Maladaptive grief reactions were recently codified in prolonged grief disorder (PGD) criteria in both DSM-5-TR (American Psychiatric Association, 2022) and ICD-11 (World Health Organization, 2022).*

- The DSM-5-TR version contains important developmental modifications *(Kaplow, Layne, Pynoos, Cohen, & Lieberman, 2012; Layne et al., 2019; Layne et al., 2020)*. Table 1 presents DSM-5-TR diagnostic criteria for PGD (Column 1), symptoms (Column 2) and developmental modifications (Column 3).

Criterion	Feature or Symptom *(see APA, 2022)*	Developmental Modifications/Qualifiers
A	The death, at least 12 months ago, of a person who was close to the bereaved person.	At least 6 months for children
B	Development of a persistent grief response characterized by one or both of symptoms B_1 and B_2, which have been present most days to a clinically significant degree. Symptom(s) must have occurred nearly every day for at least the last month.	Distress may be expressed in play and behavior, developmental regressions, and anxious or protest behavior at times of separation and reunion.
B_1	Intense yearning and/or longing for the deceased.	Children may express yearning in thought and play as a wish to physically reunite with the deceased in a physical sense (e.g., to climb a ladder to heaven)
B_2	Preoccupation with thoughts or memories of the deceased person.	Also includes preoccupation with the circumstances of the death (e.g., intense distress, anger, confusion over the traumatic and/or tragic way in which they died)
C	At least three C symptoms have been present most days to a clinically significant degree. Symptoms have occurred nearly every day for at least the last month.	
C_1	Identity disruption (e.g., feeling as though part of oneself has died).	May include feeling profoundly different from others, often in response to loss reminders (e.g., watching other children enjoy spending time with their fathers).
C_2	Marked sense of disbelief about the death.	Young children may engage in searching for the deceased because they do not understand the permanence of death.
C_3	Avoidance of reminders that the person is dead.	May be characterized by efforts to avoid reminders. May verbally (in behavior or through emotional withdrawal) show reluctance to join in activities that serve as loss reminders.
C_4	Intense emotional pain (e.g., anger, bitterness, sorrow) relating to the death.	May experience intense emotional pain over feeling deprived (“robbed”) of the deceased’s help with developmental tasks (e.g., menses; important life decisions).
C_5	Difficulty reintegrating into one’s relationships and activities after the death (e.g., engaging with friends, planning for the future).	Failure to achieve age-appropriate developmental milestones or developmental transitions may reflect difficulty with reintegrating into life activities.
C_6	Emotional numbness due to the death	Young children typically do not understand or describe numbing; adolescents may describe “not feeling anything.”
C_7	Feeling that life is meaningless due to the death.	For older children and adolescents, may include giving up on developmental aspirations, not caring about risky behavior, or feeling that their future is “ruined;” may be apprehensive over sharing a similar fate as the deceased (e.g., doomed to undergo a tragic premature death).

C8	Intense loneliness due to the death.	May be intensified by keeping grief private (e.g., wishing to avoid adding to the distress of a grieving caregiver or presumed stigma from peers).
D	Clinically significant distress or impairment in important areas of functioning.	Functional impairment appears in developmentally salient life domains (e.g., school, peers). Developmental disruption may manifest as developmental freezing, slowdowns, regressions, reluctance to take on age-appropriate developmental tasks, precocious developmental accelerations, or reckless behavior *(Layne, 2021)*.
E	Duration and severity of grief reactions clearly exceed expected social, cultural, or religious norms for the person's culture and context.	Not achieving culturally-linked developmental rites of passage may be an indicator of functional impairment and/or developmental disruption.
F	Differential diagnosis reveals that symptoms are not better explained by another mental disorder (depression, PTSD) or to the physiological effects of a substance (e.g., medication, alcohol) or another medical condition.	Clinicians should take care to avoid diagnostic overshadowing with other common disorders (e.g., depression, attention deficit disorder; PTSD) *(Layne, Kaplow, & Youngstrom, 2017)*.

- Detailed descriptions of age-specific features are available elsewhere *(e.g., Kaplow et al., 2012; Layne et al., 2019; 2020)*. More broadly, as reflected in the "Criterion B" symptom cluster, intense yearning or longing for the deceased person, preoccupation with thoughts or memories of the deceased person, and in bereaved youth, preoccupation with the circumstances of the death, are considered "gateway" symptoms that can, if severe and persisting, lead to the full constellation of PGD *(APA, 2022)*. Thus, the early presence of B symptoms may serve as markers of risk for PGD that signal a need for early intervention to prevent PGD *(Layne, 2021)*.

Developmental and contextual factors.

- Children's grief reactions also depend on contextual factors that can moderate the effects of bereavement *(Kaplow et al., 2012; Layne et al., 2019)*. These factors include:
    - Time elapsed since the death (normative grief reactions generally tend to reduce in frequency and intensity over time; clinically significant maladaptive grief reactions are characterized by a severe persisting course)
    - Relationship to the deceased
    - Circumstances of the death (e.g., traumatic or tragic vs. peaceful death)
    - Quality of one's relationship with the deceased (e.g., close vs. conflicted vs. ambivalent)
    - Family factors (economic strain, well-being of surviving caregivers)
    - Parenting practices/quality of the parent-child relationship (disruptions vs. stability in daily routines)
    - Cultural mores for grieving and mourning
    - Developmental stage: In younger children, separation distress may be predominant; in older children and adolescents, distress over disruptions in social identity (e.g., confusion about purpose in life) and risk for comorbid depression may be more manifest *(APA, 2022)*
    - Developmental or mental disability (e.g., ability to understand death; heavy dependence on the deceased)

Vulnerability factors. *Vulnerability factors increase the likelihood of severe persisting grief reactions following bereavement (Layne, 2021;* Prigerson, Kakarala, Gang, & Maciejewski, 2021; Simon et al., 2020*)*.

- Vulnerability factors include:
    - Prior history of depression
    - Prior history of trauma or loss
    - Insecure attachment style
    - Loss of a central relationship that affirmed one's personal identity and sense of life purpose
    - Heavy dependence on the deceased (e.g., primary breadwinner, primary caretaker)
    - Manner of death (e.g., characterized by suddenness, violence, deep tragedy, intense suffering, violation of the social contract)

- Major secondary adversities (loss of income, security, social connections)
- Impaired primary caregivers (compromised parenting practices)

- Other vulnerability factors include difficulties in coping with loss reminders (reminders of the deceased's ongoing physical absence), and difficulties in coping with trauma reminders (distressing reminders of how a loved one died following traumatic bereavement).

Bereavement-informed care. *Bereaved youth can experience comforting and constructive grief reactions to the death of loved ones that facilitate positive adjustment.*

- Grieving within an adaptive range is the norm, presenting in the majority of cases (Layne et al., 2019). The frequent occurrence of adaptive grief reactions (and co-occurrence with maladaptive grief reactions to varying degrees) can make it challenging to identify, diagnose, conceptualize, and intervene with bereaved youth.
- As examples of this complexity, grief-related personal existential crises (characterized by apathy, despair, and resignation) can be mistaken for depression, lack of life ambition, or aimlessness. Further, posttraumatic stress reactions can be evoked by exposure to wasting illness *(Kaplow, Howell, & Layne, 2014)*, and both PTSD and PGD can be evoked by traumatic bereavement *(Layne & Kaplow, 2020)*.
- Bereavement-informed care can facilitate these challenging tasks *(Layne, 2021)*. Components include:
  - Guiding strength-based theory that helps clinicians to differentiate between helpful versus unhelpful grief reactions, integrate ecological factors (e.g., parenting practices), and address developmental factors and impacts (e.g., multidimensional grief theory—Layne et al., 2017, 2019)
  - Developmentally-appropriate assessment tools *(Layne, Kaplow, & Pynoos, 2022)* that support evidence-based assessment *(Layne, Kaplow, et al., 2017; Layne & Kaplow, 2020)*.
  - Interventions that can both facilitate adaptive grief reactions and therapeutically reduce maladaptive grief including PGD *(Saltzman et al., 2017; Kaplow, Layne, Pynoos, & Saltzman, in press)*.
  - A training curriculum that guides learners through risk identification, differential diagnosis, and strength-based case conceptualization and treatment planning. For example, motivational interviewing strategies can help to shift bereaved youth away from maladaptive ways of grieving and mourning towards adaptive ways of grieving and mourning *(Layne, 2021)*.

Guidelines for Supporting Bereaved Youth.

- Guidelines include *(Kaplow, Layne & Pynoos, 2019, Layne, 2021)*:
  - Listen empathically and non-judgmentally; help them to label and understand their emotions.
  - Utilize the power of simple gifts (understanding, lightening a load, helping them connect to others).
  - Reflect and paraphrase (not only what they say, but how they say it—attend to voice tone, pacing).
  - Mobilize social support. This can include both teaching bereaved youth to recruit social support, and members of their social networks to furnish support *(Saltzman et al., 2017)*.
  - Promote caregiver well-being and role functioning, recognizing that they may also be experiencing significant grief reactions and contending with major adversities.
  - Focus on self-care (sleep, diet, exercise, rest, socializing).
  - Clarify that grieving takes time and energy and may be partially postponed amidst urgent problems.
  - Help bereaved families understand that people grieve in different ways; normalize and validate dyssynchronies that can emerge in families and other social networks.
  - Suicide ideation can reflect intense longing to be reunited with the deceased in an afterlife or an existential or identity crisis. These powerful motivations can be validated and integrated into grief-informed suicide prevention.
  - Join a risk screening & referral network that uses developmentally appropriate assessment tools *(Layne, Kaplow, & Pynoos, 2022)* and grief-informed interventions *(Saltzman et al., 2017; Kaplow, Layne, Pynoos, & Saltzman, in press)*.

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