Chapter 93: Prolonged Grief Disorder

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INTRODUCTION

Bereavement is the most common and distressing type of adverse life event reported among children and is associated with significant long-term psychological, behavioral, and physical health consequences including suicidal ideation, problematic educational outcomes, and susceptibility to both chronic and infectious diseases. In 2015, the United Nations International Children's Emergency Fund (UNICEF) estimated that worldwide nearly 140 million children under age 18 had experienced the death of 1 or both parents. In the US general population, 7.7% of children (5.6 million) will experience parental death, and 1.5% will experience a sibling death before age 18; these rates are elevated in times of natural disasters, pandemics, and war. For example, at the time of this writing, there are now over 290,000 US youth who have lost a parent or primary caregiver to COVID-19.

Most youth go through an emotionally painful but natural grieving process whereby the intensity of grief-related distress tends to ebb and flow, especially in response to reminders of the loss, but typically lessens over time. This assumption of the fundamentally beneficial, normative, and adaptive nature of grief has critical implications for efforts to conceptualize, assess, diagnose, and treat prolonged grief disorder (PGD). Although most bereaved children grieve in adaptive and healthy ways and maintain "normal functioning" across life domains, an important subset of children can develop persistent and severe symptoms of "maladaptive grief" associated with significant functional impairment that extends beyond cultural norms. These signs and symptoms of maladaptive grief were insufficiently captured by existing diagnostic categories, resulting in the inclusion of the candidate diagnosis Persistent Complex Bereavement Disorder (PCBD) in the Appendix of the Diagnostic and Statistical Manual for Psychiatric Disorders, Fifth Edition (DSM-5). After 3 years of careful consideration, the American Psychiatric Association concluded that the PCBD diagnostic criteria (slightly modified and renamed as Prolonged Grief Disorder) were sufficiently valid, comprehensive, clinically useful, and empirically distinct from "normative grief reactions" and other established disorders to merit the inclusion of PGD as a formal diagnosis in the Diagnostic and Statistical Manual for Psychiatric Disorders, Fifth Edition, text revision (DSM-5-TR). PGD is also included in the 11th edition of the International Classification of Diseases (ICD-11).

PHENOMENOLOGY AND DIAGNOSTIC CRITERIA

In contrast to a normative grieving process in which the intensity and phasic reactivity to reminders of the deceased person or reminders of the circumstances of the death gradually diminish with time, PGD involves distressing grief reactions that persist and/or grow over time coupled with chronic functional impairment. Specific criteria include intense yearning or preoccupation regarding the deceased person (Criterion B), accompanied by at least 3 of 8 symptoms of: identity disruption, disbelief about the death, avoidance, emotional pain related to the loss, difficulties moving on with life, emotional numbness, a sense that life is meaningless, and intense loneliness, nearly every day or more often for at least 1 month (Criterion C), that cause distress or functional impairment (Criterion D), exceed cultural and contextual norms (Criterion E), and are not better explained by another mental disorder or substance (Criterion F).

Criteria for PGD as per the ICD-11 similarly include "persistent and pervasive longing for and/or persistent preoccupation with the deceased, accompanied by any of the 10 symptoms that indicate intense emotional pain (eg, sadness, guilt, anger, denial, blame, difficulty accepting the death, feeling one has lost a part of one's self, an inability to experience positive mood, emotional numbness, and difficulty in engaging with social or other activities) for at least 6 months following bereavement." The ICD-11 also includes a cultural caveat that specifies that grief reactions, both in terms of the duration of symptoms as well as the manifestation of grief, must clearly violate "expected social, cultural, or religious norms for the individual's culture and context."

Developmental Considerations

To ensure that the PGD diagnostic criteria are appropriate for children and adolescents, specific developmental modifications have been incorporated into the diagnosis itself. First, although adults can only be diagnosed with PGD once at least 12 months have passed since the death (Criterion A), PGD can be diagnosed in children and adolescents if at least 6 *months* have passed since the death. This modification was made for several reasons. First, children who are likely to exhibit more severe maladaptive grief reactions will generally do so within the first several months of the death. Second, a full year in a child's life can span a major developmental period and may constitute a lost opportunity for timely remediation. Finally, given children's reliance on their caregiving environment to facilitate adaptive grieving, the capacity to identify early signs of significant maladjustment may also help to promote effective caregiver facilitation of children's adaptation post-loss.

With regard to Criterion B of PGD, children's intense yearning for the deceased may be expressed through disruptions in normal daily rhythms and/or through their play, especially among very young children, often resulting in significant impairments including developmental regressions (eg, language delays, difficulties with eating or toileting). In addition, "preoccupation regarding the deceased" in children can also include preoccupation with the circumstances of the death, which may involve intrusive and distressing images of the person who died (eg, the progressive, physical deterioration of a loved one who died of a prolonged illness). Avoidance of reminders in children can also be characterized by "efforts to avoid" reminders (eg, hesitancy or reluctance to join in activities that may remind the child of the person's physical absence). Finally, difficulties "moving on with life" may manifest in children or adolescents as failure to achieve normal developmental milestones.

DIAGNOSTIC PREVALENCE

As a result of the recent addition of PGD to the DSM-5-TR and ICD-11, there has been an uptick in studies evaluating PGD among adults. However, far fewer studies have examined PGD or other bereavement-related disorders among youth, in part due to the lack of developmentally informed assessment tools designed to evaluate children's maladaptive grief reactions. In a population-based sample of parentally bereaved children and adolescents (ages 7–18) that completed the Inventory of Complicated Grief (ICG)—a measure that primarily assesses separation distress—approximately 10% reported high and sustained prolonged grief symptoms nearly 3 years after parental death. In a clinic-referred sample of 367 bereaved youth aged 8 to 18 who completed the Persistent Complex Bereavement Disorder (PCBD) Checklist, 18% met full diagnostic criteria for PCBD. In a 2019 study of 291 bereaved youth aged 8 to 18, 12.4% met diagnostic criteria for PGD as per ICD-11 criteria, which was lower than PGD rates in a sample of bereaved adults (18%). Additional epidemiological studies that utilize developmentally informed and culturally sensitive measures of PGD are needed to clarify the prevalence of PGD.

PRESENTATION OF SYMPTOMS

Multidimensional Grief Theory

Although the PGD diagnostic criteria are useful with regard to identifying grief reactions that may impede functioning in youth, the criteria themselves are not grounded in a particular theory of grief and do not include aspects of "adaptive" grieving. Viewing PGD criteria through the lens of multidimensional grief theory can offer clinical insights regarding the manifestations of grief, including both maladaptive and adaptive features, in children of different ages. Developed by Drs. Christopher Layne, Julie Kaplow, and Robert Pynoos, multidimensional grief theory proposes that childhood grief reactions can be characterized by 3 broad dimensions: Separation Distress, Existential/Identity Distress, and Circumstance-Related Distress. The theory is based on the assumptions that both maladjustment and positive adjustment can manifest within each domain, and that positive and negative adjustment processes can and frequently do co-occur within a single domain.

Separation Distress involves distressing reactions to the continuing physical absence of and the inability to physically reunite with the deceased person. Common initial manifestations of separation distress are characterized by missing the deceased person; heartache over their failure to return; and pining, yearning, and longing to be reunited with them—often as evoked by loss reminders (people, places, things, or situations that remind the child of the person's physical absence). Young children may exhibit separation distress by continuing to visit the last place they saw the deceased person or by demonstrating increased fear around separating from adult caregivers. Children struggling with separation distress may also experience developmental regressions (eg, language delays, difficulties eating or sleeping), and in older youth, developmental slowing may be motivated by desires to stay connected with the deceased by remaining stuck in the same developmental stage, life circumstances, or immature/self-defeating behavior patterns they exhibited while the person was still alive. Severe separation distress can also manifest as ongoing suicidal ideation, reflective of the persisting desire to be reunited with their loved one. In contrast, adaptive aspects of separation distress can involve finding healthy ways of feeling connected to the deceased person (eg, engaging in activities or behaviors that the child and deceased used to participate in together) and/or

reinventing the relationship from a physical nature to a more spiritual one, or one that involves a continued sense of positive, protective guidance from the deceased.

Existential or Identity Distress refers to the altered sense of self and existential meaning one attributes to life after the death of a loved one, including the belief that their life is now ruined or that they will share the same fate (eg, early death) as their loved one. Maladaptive reactions to existential/identity-related challenges may manifest as severe disruptions in one's sense of self or one's sense of purpose and meaning (eg, life aspirations, future plans, and ambitions). Existential distress may manifest behaviorally in the form of lethargy, anhedonia, or social withdrawal in younger children. Young children may also experience fears and concerns related to daily life (eg, who is going to take me to school, brush my hair, help me with my homework, etc.). Both children and adolescents may express discontinuity in identity as shame or embarrassment surrounding the loss, as they may now feel different from others and subsequently self-conscious (eg, "I'm different from other kids because I don't have a mother anymore"). Existential or identity crises may also manifest in adolescents as extreme risk-taking or recklessness, tempting fate, indifference to one's safety or well-being ("I don't care if I live or die") and/or feeling like life is meaningless ("It's not worth trying" or "Nothing really matters anymore"). They may also anticipate future losses, which can interfere with their ability to form lasting relationships. In contrast, adaptive forms of existential/identity distress can involve finding ways of living the legacy of the person who died or doing things that would have made the deceased person proud (eg, running a marathon that the person never had a chance to do or pursuing a career that the person would have highly valued).

Child bereavement studies, more so than adult studies, have raised the importance of circumstance-related distress in childhood and its reverberations with regard to both immediate and long-term developmental consequences. Circumstance-Related Distress involves troubling thoughts and emotional pain over the particular manner of death and is theorized to increase in response to deaths that have occurred under tragic and potentially traumatic conditions (eg, fatal accidents, homicide, suicide, prolonged physical deterioration of a dying parent). Maladaptive responses may include distressing mental images regarding the circumstances of the death, intense negative emotions (anger, rage, horror, revulsion, shame), distressing thoughts and beliefs regarding the manner of death, including self-blame and blame of others, confusion, feeling shocked over how they died, and retaliatory or intervention fantasies. Young children may exhibit circumstance-related distress by "playing out" the death in pretend play or through the use of toys, whereas older youth may ask repeated questions about the manner of death. In contrast, adaptive forms of circumstance-related distress can involve attempts to transform the circumstances of the death into something that can help others to avoid suffering in the same way (eg, raising money for a certain cause related to the person's death such as cancer, entering a specific profession that could help save lives or further the pursuit of social justice).

Differential Diagnosis

Recent studies that have examined symptoms of PGD in children and adolescents offer support for the distinctiveness of PGD from other disorders. These studies generally demonstrate that the PGD symptoms of intense yearning, difficulties in accepting the loss, anger, and a sense that life is meaningless constitute a unique cluster of grief symptoms with distinct causal origins and causal consequences that can be distinguished from other disorders that often occur after a death, including PTSD and depression. In addition, prolonged grief is significantly and uniquely related to functional impairment in youth following the death of a loved one, even after accounting for PTSD and depression. Finally, prolonged grief can be further distinguished from most other psychiatric disorders that do not have an "adaptive" counterpart. For instance, unlike PTSD and depression, grief is generally conceptualized as inherently beneficial and adaptive and only in rare cases involves functional impairment.

RISK FACTORS

Demographic Risk Factors

Among the few studies of demographic correlates of grief among children, findings are mixed. A population-based study of adolescents aged 12 to 19 found no gender differences in mean levels of maladaptive grief symptoms, whereas a study of 240 youth aged 6 to 17 showed that girls reported higher scores than boys (although the grief assessment tool measured a combination of grief and traumatic stress symptoms). With regard to race and ethnicity, research suggests youth of color may be at higher risk for experiencing maladaptive grief reactions compared to white youth. A 2021 study of youth aged 6 to 18 found that compared to white youth, both black and Latinx youth reported higher maladaptive grief reactions. This finding may have been due to the fact that black youth were more likely than white youth to lose a loved one to homicide that, in turn, was associated with higher levels of separation distress and circumstance-related distress. This study highlights the importance of considering contextual factors that may help explain racial disparities as well as cultural factors that shape the way youth experience and cope with bereavement.

Circumstances of the Death

Deaths that are characterized by violence, such as suicide or murder, can complicate children's grief reactions due to the increased likelihood of associated traumatic and distressing thoughts, feelings, and images interfering with a normative and healthy grief response. Such intrusive thoughts can include wishes and regrets about the way that the person died, shame or guilt over not being able to save the person, and/or intervention fantasies. Issues of human accountability can also lead to lengthy legal proceedings, conflicts among family members, guardianship issues, stigma, and conspiracies of silence that often complicate and/or compromise the child's caregiving environment, leading to further grief-related distress. For example, violent deaths have been associated with increased anxiety, depression, and maladaptive grief in adolescents.

Studies also suggest that anticipated or illness-related losses, including terminal cancer, may be particularly distressing for children. A 2014 study of parentally bereaved youth found that children who lost a caregiver due to a prolonged illness exhibited higher levels of both maladaptive grief and posttraumatic stress symptoms when compared to children who lost a caregiver due to sudden natural death (eg, heart attack). The very nature of anticipated deaths may create more instances in which children are exposed to potentially distressing elements (eg, witnessing disturbing medical procedures and/or the dying person's progressive deterioration during repeated hospital visits) and accompanying intrusive preoccupations that may interfere with adaptive grief processes.

Relationship to the Deceased

Another important factor that can influence children's grief reactions is the relationship to the deceased person. The loss of "primary relationships" (eg, parent/caregiver) typically involves more intense psychological distress compared to "secondary" losses (e.g., extended family members, acquaintances). For example, in the context of a sniper attack, children who lost a primary attachment figure were more likely to exhibit prolonged grief symptoms, primarily characterized by separation distress, compared to youth who lost a friend or an extended family member. The nature and quality of the relationship to the deceased is also important, as research shows that relationships with the deceased that were close, supportive, and confiding are associated with an increased risk of maladaptive grief symptoms.

History of Prior Trauma, Loss, or Mental Health Issues

Several additional risk factors for developing PGD or maladaptive grief reactions have been identified. Recent studies suggest that youth with prior histories of depression or anxiety and/or a family history of anxiety disorders are at greater risk for developing PGD. Additional risk factors include having experienced prior losses or having been exposed to prior traumas.

PROTECTIVE FACTORS

Caregiving Environment

Children and adolescents rely heavily on the adults in their environment to navigate and cope with the death of a loved one, making the caregiving context one of the most critical factors in facilitating adaptive grief. The availability of a primary attachment figure in the aftermath of a death can help reduce fear and other negative emotions related to the loss, help reestablish normal routines, and serve as a biobehavioral regulator. Several aspects of the caregiving context that can serve as protective factors include providing effective social support, warmth, open communication, and positive parenting (eg, adherence to routines, predictable schedules, and positive family activities). Additionally, some recent studies have highlighted the importance of specific caregiving behaviors that can facilitate adaptive grief in children such as reminiscing and talking about the deceased, discussing positive qualities that the child has in common with the deceased person, and sharing happy memories.

ASSESSMENT OF PROLONGED GRIEF DISORDER

Few validated tools designed to assess PGD in youth currently exist. The primary available tool is the Prolonged Grief Disorder Checklist, a developmentally sensitive and culturally informed measure that can be used to diagnose PGD in children and adolescents ages 7 to 18. The PGD Checklist consists of both a *Youth Self-Report* and an optional *Adult Caregiver Observational Report* version. Youth Self-Report elements include 5 items assessing basic demographic variables; 4 items assessing factual information regarding the death, its circumstances, and relationship to the deceased (Criterion A); 25 items assessing grief reactions to the death (Criteria B and C); and 10 items assessing the youth's perception of how much their grief reactions cause (a) clinically significant distress (1 item), and (b) functional impairment in important life domains including home, school,

peers, and developmental progression (9 items) (Criterion D). The PGD Checklist can also be scored according to multidimensional grief theory to derive 3 primary subscales that directly align with each of the dimensions of grief: separation distress, existential distress, and circumstance-related distress, allowing for selective intervention foci to address specific areas of ongoing concerns and impairments in daily life. The PGD Checklist also includes optional "adaptive grief" items that can reinforce strengths of both the individual child and the family context.

Other assessment tools have been developed that measure youth's grief reactions, although these tools do not necessarily capture specific developmental manifestations of grief. For example, originally developed for adults, The Texas Revised Inventory of Grief (TRIG)–Present Feeling Subscale is a 13-item self-report measure of children's current feelings about the death (eg, "I still cry when I think of my___"). The TRIG primarily captures normative aspects of grief. The Inventory of Complicated Grief–Revised Child (ICG-RC) has also been used to assess maladaptive grief in children. This tool was adapted from the Inventory of Complicated Grief (ICG), which was originally developed and validated with widows over the age of 65 and focuses almost exclusively on symptoms of separation distress.

EVIDENCE-BASED INTERVENTIONS FOR CHILDHOOD PROLONGED GRIEF DISORDER

Psychotherapy

Although a number of general trauma-focused therapeutic interventions currently exist, comparatively few treatments have been developed to assist bereavement-exposed youth who are experiencing maladaptive grief reactions and/or the complex interplay of grief and trauma. Multidimensional Grief Therapy (MGT) is a theoretically derived, assessment-driven intervention designed to reduce PGD or maladaptive grieving (grief that keeps youth "stuck" and unable to adjust) and associated mental health issues (eg, PTSD, depression) while promoting adaptive grieving (grief that helps youth to cope better after a death) in bereaved children and adolescents, aged 7 to 18. This intervention is based on the notion that youth grieve in different ways and that "one-size-fits-all" grief treatments lack effectiveness. To our knowledge, MGT is the first evidence-based intervention developed specifically for bereaved children and adolescents that directly addresses all 3 dimensions of grief as described by multidimensional grief theory. The exercises in MGT are designed to target each dimension of grief (ie, separation distress, existential/identity distress, and circumstance-related distress) based upon each child's individual assessment profile as well as their developmental needs and strengths. MGT has been found to significantly reduce maladaptive grief reactions (including symptoms of PGD), depression, and posttraumatic stress among diverse populations of youth across a wide range of bereavement-related circumstances (eg, anticipated deaths due to illness, homicide, suicide, COVID-related deaths, etc.).

Given that not every child requires an intensive psychosocial treatment following a death, MGT is also designed to provide a continuum of care, spanning the needs of children who may be experiencing normative struggles after a death to those who meet full criteria for PGD. To do this, MGT uses a 2-phased approach. The first phase is designed to provide general grief support and focuses primarily on psychoeducation, normalizing grief reactions, emotion regulation skills, recognizing personal loss and trauma reminders, and positive reminiscing activities. Although Phase I can be offered in clinical settings, it can also be provided by bereavement support centers, faith-based organizations, pediatric offices, schools, or other settings that are focused on tier one supports after a death. The second phase of MGT is generally conducted by a trained clinician and is designed to address more maladaptive grief reactions through grief processing as well as identifying and replacing maladaptive thoughts such as "it was all my fault" or "I'm never going to be happy again." MGT can be implemented individually or in group settings, and sessions typically include dyadic caregiver-child practice elements.

The Family Bereavement Program (FBP) is a 12-session group treatment for bereaved caregivers and their children (ages 8–16) that aims to prevent and reduce prolonged grief and mental health problems over time. Practice elements include teaching clients positive coping strategies, skills for adaptive emotional expression, positive parenting techniques, and ways of dealing with bereavement-related stressors. FBP has been found to reduce externalizing problems, increase self-esteem, and reduce intrusive and/or disruptive grief-related thoughts.

Trauma and Grief Component Therapy (TGCT) is an assessment-driven, modularized treatment originally designed for adolescents whose histories of exposure to trauma, bereavement, and/or traumatic loss place them at high risk for severe persisting distress, functional impairment, and developmental disruption. TGCT is ideally suited for youth who may require both trauma- *and* grief-related intervention components (eg, an adolescent who may have experienced sexual abuse as well as the death of a loved one). TGCT comprised up to 4 modules, ranging from 12 to 36 weeks, depending on the specific mental health needs of participants. TGCT modules are flexibly assigned and tailored based on youths' assessment profiles. TGCT has been shown to reduce posttraumatic stress, depressive symptoms, maladaptive grief reactions, and violent behavior, while increasing rule compliance and connectedness across diverse settings and populations, including in schools following a 1988 earthquake in Armenia and the 1992–1995 Bosnian civil war, youth exposed to high rates of community violence, and in juvenile justice settings.

In cases of traumatic bereavement, in addition to MGT and TGCT, both Trauma-Focused Cognitive Behavioral Therapy (TF-CBT) and Grief and Trauma Intervention (GTI) have proven to be helpful in reducing traumatic stress reactions and preoccupations regarding the traumatic circumstances of the death and promoting more adaptive grief reactions.

Peer Support

Peer support is a common form of intervention used in pediatric settings with youth who have chronic physical health issues, and this work has been extended to youth exposed to childhood bereavement. In fact, the childhood bereavement field has relied heavily on peer support group programs to assist youth in the aftermath of a death. Operating under the assumption that bereavement and grief are natural and normal processes, peer programs help to foster healthy and safe environments in which youth can express their grief reactions and feel understood and supported by other bereaved peers and families. Despite their promise for normalizing and validating children's grief reactions, peer support alone may be insufficient for bereaved youth who are struggling with symptoms of PGD and who require focused practice elements to address specific dimensions of persistent grief and associated impairments.

Medication

No studies to date have examined the use of medication to treat PGD in children and adolescents. Similar to treatment recommendations for other forms of environmentally induced distress, psychotherapy is generally the treatment of choice. However, it is possible that adjunctive medication treatment may be helpful for common co-morbid conditions such as Major Depressive Disorder (see Chapter 90) or when there is an incomplete response to psychotherapy. Bereaved youth who have a family history or their own history of depression should be monitored carefully for depressive symptoms, which may require their own primary treatment, including medication, complemented by psychosocial treatment for PGD.

CONCLUSION

With hundreds of thousands of US youth having lost a parent or caregiver due to the COVID-19 pandemic and steep rises in deaths of despair, including drug overdose and suicide, new developments with regard to the assessment and treatment of PGD could not come at a more critical time. Identifying bereaved youth as quickly as possible and providing the right form of support at the right time can prevent both short- and long-term suffering and promote healthy development over the life course.

SUGGESTED READINGS

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