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Prolonged grief disorder in adults: Epidemiology, clinical features, assessment, and diagnosis

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INTRODUCTION

Bereavement is the situation in which a loved one has died, and grief is the response to this loss. In a minority of patients, grief may progress to prolonged grief disorder, which is a unique and identifiable syndrome marked by pervasive, intense, and functionally impairing symptoms that persist longer than expected by a person's social community, culture, or religious group. Prolonged grief disorder requires specific treatment [1,2]. Recognition of problematic grief extends back to at least 1980, when Bowlby explained how grief could lead to a state of "suspended growth in life" if certain natural defensive processes persisted too long and/or exerted undue influence upon the bereaved person's mental functioning [3].

This topic reviews the epidemiology, clinical manifestations, assessment, diagnosis, and differential diagnosis of prolonged grief disorder. Treatment of prolonged grief disorder is discussed separately, as is bereavement, grief, and palliative care.

- (See "Prolonged grief disorder in adults: Treatment".)
- (See "Bereavement and grief in adults: Clinical features".)
- (See "Bereavement and grief in adults: Management".)
- (See "Benefits, services, and models of subspecialty palliative care".)

TERMINOLOGY

The terms bereavement, grief (acute and integrated), mourning, and prolonged grief disorder describe different aspects related to the death of a loved one [4-7]:

- **Bereavement** – The situation in which someone who is close dies (rather than the reaction to that loss). (See "Bereavement and grief in adults: Clinical features", section on 'Bereavement'.)

- **Grief** – Grief is the natural response to bereavement, and includes thoughts, feelings, behaviors, and physiologic reactions. Although grief can occur in response to other meaningful, nonbereavement losses (eg, loss of a job, divorce, or migration), this topic focuses upon grief in response to the death of a loved one.

  The pattern and intensity of grief varies over time and evolves as bereaved individuals adapt to the loss. The experience of grief is unique to each person and each loss and is influenced by cultural and religious rituals and social expectations. Progress from acute to integrated grief is often erratic and may be hard to discern as it is happening. (See "Bereavement and grief in adults: Clinical features", section on 'Typical acute grief'.)

- **Mourning** – Mourning is the process of adapting to a loss and integrating grief. Adaptation entails accepting the finality and consequences of the loss and a changed relationship with the deceased, restoring the capacity to thrive, and re-envisioning the future with the possibility for happiness and meaning in a world without the deceased. When mourning is successful, the painful and disruptive experience of acute grief is transformed into an experience of integrated grief that is bittersweet, in the background, and permanent. Like grief, mourning is influenced by personal, cultural, and religious beliefs and rituals that vary widely.

- **Prolonged grief disorder** – Prolonged grief disorder is a form of grief that is unusually protracted, intense, and disabling. The disorder is characterized by maladaptive thoughts, dysfunctional behaviors, dysregulated emotions, and/or serious psychosocial problems that impede adaptation to the loss. The syndrome of prolonged grief disorder is a unique and recognizable condition that can be differentiated from other psychiatric disorders. Other names that have historically been used for prolonged grief disorder include chronic grief, complex grief, complicated grief, pathological grief, persistent complex bereavement disorder, traumatic grief, and unresolved grief. (See 'Clinical features' below and 'Diagnostic criteria' below.)

EPIDEMIOLOGY

Prolonged grief disorder is found across a wide range of cultures and across the lifespan [8].

General population — The estimated lifetime prevalence of prolonged grief disorder in the general population is approximately 2 to 5 percent [9,10]; however, the rate varies across studies due to methodologic differences such as different sampling procedures and different methods of identifying the syndrome.

Bereaved

- **General population that is bereaved** – In the subset of the general population that is bereaved, the point prevalence of prolonged grief disorder is approximately 10 percent, based upon a meta-analysis of 14 community studies [11]. However, this estimate is provisional, given the large heterogeneity across studies and the absence of standard criteria for prolonged grief disorder when the underlying studies were conducted. Most of the studies did not utilize population-based representative samples, and the estimate was derived from samples bereaved by nonviolent means. In most of the larger studies, bereavement consisted primarily of parental deaths. Additionally, six different instruments were used to establish the presence of prolonged grief disorder.

  The prevalence of prolonged grief disorder among the bereaved varies according to the relationship to the deceased. Among bereaved individuals who lose a spouse, the estimated rate of prolonged grief disorder is 10 to 20 percent [4,12], whereas a study of parents who lost a child found the rate was 60 percent [13].

- **Individuals bereaved by violent causes** – Prolonged grief disorder is more prevalent among those bereaved by violent causes (also referred to as “unnatural”), such as accidents, homicides, natural disasters, suicides, and wars. A meta-analysis of 25 studies (n >4700 bereaved) found that following violent losses, the prevalence of prolonged grief disorder was nearly 50 percent [14]. However, heterogeneity across studies was large, and many studies did not accurately represent the target population due to sampling methods.

- **Bereaved refugees** – Prolonged grief disorder may also be common in migrating refugees. In a meta-analysis of four studies that surveyed bereaved refugees (n = 479), most of whom had experienced war-related bereavement, the point prevalence of prolonged grief disorder was 33 percent [15]. However, heterogeneity across studies was large, and one study simply asked respondents if they still had strong grief when thinking about the deceased.

Clinical settings — Rates of prolonged grief disorder appear to be elevated in psychiatric and general medical settings. As an example, the prevalence among patients with unipolar major depression or bipolar disorder is approximately 20 percent:

- Unipolar major depression
  - Inpatients (n = 73) – 18 percent [16]
  - Outpatients
    - General clinic (n = 111) – 20 percent [17]
    - Veterans (n = 1522) – 19 percent [18]
- Bipolar disorder (n = 120 outpatients) – 21 percent [19]

Military personnel — Prolonged grief disorder may also be common among military personnel who present to clinical settings, with rates of approximately 30 percent:

- In a cross sectional study of 468 treatment-seeking veterans or active-duty service members who had lost someone close (eg, relative or fellow service member), prolonged grief disorder was present in 30 percent [20].
- The same group of investigators conducted a randomized trial that included treatment-seeking veterans or service members with combat-related posttraumatic stress disorder who were bereaved (n = 160); the prevalence of prolonged grief disorder among the bereaved was 31 percent [21].

Risk factors — Studies of bereaved individuals have identified potential risk factors for prolonged grief disorder, including [4,7,9,22-30]:

- Older age (eg, >61 years)
- Female sex
- Low socioeconomic status
- Racism, inequity, and disparities
- Lifetime psychiatric history (eg, anxiety and depressive disorders)
- Bereaved of a child or spouse
- Death of a young person
- Death by violent means (eg, accident, homicide, natural disaster, or suicide)
- Bereaved multiple times

Other factors that may increase the likelihood of prolonged grief disorder include caregiver burden and impaired family functioning prior to the death [26,31], as well as difficult or troubling circumstances or consequences of the death, such as overly aggressive medical

interventions, perception of uncaring medical staff, or uncertainty about the cause of death [26]. Among individuals with a terminally ill family member, those who manifest high levels of prolonged grief disorder symptoms prior to the death may be more likely to develop the disorder after the loss [32].

Anxious attachment style also appears to be a risk factor for prolonged grief disorder, especially when there is a strong, positive relationship with the deceased [26]. Those with anxious attachment worry that others will not be available in times of need [12,13,33]. Insecure attachment style, which is a trait-like characteristic that is associated with anxiety and depressive disorders, may also increase risk for prolonged grief disorder.

PATHOGENESIS

The pathogenesis of prolonged grief disorder is not known [34]. However, preliminary studies suggest that prolonged grief disorder is associated with distinct neurobiological processes that reflect a chronic stress reaction [35]. In addition, multiple psychological models of prolonged grief disorder have been proposed [36], including one based upon loss of an attachment relationship [33,37] and another model based upon cognitive behavioral theories [7].

Neurobiology — Prolonged grief disorder may be associated with a distinct neurobiological profile [38,39]. A review of 24 studies found evidence that suggests the disorder involves dysregulated signaling in central nervous system regions related to reward [40]. Normative grief was distinguished from prolonged grief by differences in activity of the amygdala and orbitofrontal cortex, and these differences may also extend to the posterior cingulate cortex and basal ganglia, including the nucleus accumbens. One small study used functional magnetic resonance imaging (MRI) of bereaved women (prolonged grief disorder, n = 11; integrated grief, n = 12) to examine the effects of idiographic cues of the deceased, such as a picture [34]. Both groups showed neural activity in brain regions linked to pain (eg, anterior cingulate cortex). However, activity in the nucleus accumbens, which is associated with reward, was greater in women with prolonged grief disorder than women with integrated grief. The investigators hypothesized that activation of central nervous system reward centers by reminders of the deceased may interfere with adapting to the loss.

Modest differences in brain structure may also be present in prolonged grief disorder. A study of individuals with prolonged grief disorder (n = 155) and nonbereaved individuals (n >3100) who underwent MRI found that after controlling for potential confounding factors (eg, age, alcohol consumption, and history of depression and diabetes), total brain volume was smaller in

those with the disorder [41]. However, there was no bereaved control group and the difference was clinically small.

In addition, prolonged grief disorder may be associated with abnormalities in neuroendocrine systems. A study examined salivary cortisol levels in persons who experienced a loss in the past two years, including individuals with prolonged grief disorder (n = 31), normal/integrated grief (n = 131), or no grief (n = 1922) [35]. Morning and diurnal cortisol levels were lower in participants with prolonged grief disorder, compared to those with normal grief and no grief, suggesting a chronic stress reaction. Cortisol levels were comparable in participants with normal grief and no grief.

Differential gene expression has also been observed in prolonged grief disorder. A study enrolled individuals bereaved on average for two years after losing their spouses/partners, including those with prolonged grief disorder (n = 12) and those without the disorder (n = 24) [42]. Prolonged grief disorder was associated with down regulation of genes involved in antiviral and pro-inflammatory responses. If confirmed, this could help explain the association between prolonged grief disorder and increased health risks. (See 'General medical' below.)

Loss of an attachment relationship — Multiple studies corroborate a psychobiological attachment system that motivates people to form and maintain close relationships [33,37,43,44]. These relationships affect physiological and psychological functioning, and contribute to one's sense of safety, interest, competence in autonomous functioning, and to feelings of mattering and belonging in the world. Losing an attachment relationship has extensive consequences, and adapting to this loss is difficult and takes time. Adaptation involves accepting the reality that a loved one is gone forever and all that this means, accepting a changed relationship with someone so important in one's life, and moving forward in life without this person.

It is hypothesized that processes to support adapting to loss are part of the attachment system and occur automatically if nothing interferes. However, adaptation is sometimes impeded by defensive thoughts, feelings, and behaviors that typically occur early in acute grief, if they persist for too long or exert undue influence on mental functioning [3]. The risk that adaptation/integration will not occur is exacerbated by severe environmental stress or co-occurring psychiatric or general medical illness [30]. The result is prolonged grief disorder. Additional information about loss of attachment and bereavement is discussed separately. (See "Bereavement and grief in adults: Clinical features", section on 'Loss of attachment'.)

CLINICAL FEATURES

This topic focuses upon prolonged grief disorder in response to the death of a loved one. However, it appears that a form of this condition also occurs in response to other meaningful, nonbereavement losses, including loss of a relationship (eg, divorce or missing person), pet, job, or community (eg, migration). In a study of survivors of a natural disaster who showed signs of unusually prolonged, intense, and disabling grief (ie, prolonged grief disorder), the large majority of survivors suffered nonbereavement losses [24]. The prevalence of prolonged grief disorder symptoms was highest after loss of a loved one but the absolute number of people with this condition was highest after nonbereavement loss.

Signs and symptoms — The clinical features of prolonged grief disorder consist of emotional, cognitive, and behavioral reactions to the death of a loved one, including [5,10,44-55]:

- Intense and persistent grief that lasts at least 6 to 12 months after the loss and is accompanied by evidence of persistent psychic pain:
  - Separation distress – Yearning for and preoccupation with the deceased, as well as feelings of sorrow, frustration, anxiety, and guilt
  - Inhibited exploration of the world – Loss of interest in ongoing life, difficulty envisioning a meaningful life without the deceased, and feeling disconnected from others
  - Traumatic distress – Disbelief and difficulty accepting the death; feeling stunned, dazed, lost, unfocused, or emotionally numb; and intrusive thoughts or images of the death
- Persistence of early grief defensive processes, such as:
  - Disbelief and/or protest
  - Imagining and ruminating upon alternative scenarios to the death (counterfactual thinking)
  - Caregiver self-blame or anger that may take the form of rumination (eg, "I could have prevented the death," "I could have made his life easier," or "I should have told her that I loved her")
  - Intense emotional and/or physiologic reactions (eg, increased somatic symptoms and/or insomnia) to reminders of the loss
  - Maladaptive behaviors, characterized by either of the following:

- Excessive avoidance of reminders of the loss

- Trying to escape from the reality of the loss by excessively seeking closeness to the deceased through sensory stimulation (eg, looking at pictures or keepsakes, listening to the person's voice on a recording, or smelling the person's clothes) or frequenting the loved one's place of rest

- Difficulty regulating emotions, which manifests with problems such as trouble experiencing emotions and setting them aside, as well as difficulty experiencing and appreciating positive emotions

- Impaired functioning, such as impaired concentration, inability to perform daily activities, or difficulty trusting or caring for others

Two signs and symptoms that are particularly common in prolonged grief disorder are yearning for the deceased and feeling upset by memories of the deceased [23]. As an example, one study of patients with prolonged grief disorder (n = 288) found that the most frequent symptoms were [47]:

- Yearning for the deceased – 88 percent of patients
- Feeling upset by memories of the deceased – 82 percent
- Loneliness – 81 percent
- Feeling life is empty – 80 percent
- Disbelief – 76 percent
- Inability to accept the death – 70 percent

Sleep disturbance may also be common [56].

Social problems can supervene in the aftermath of a loss and become the focus of thoughts and behaviors, interfere with mourning, and may lead to prolonged grief disorder. As an example, a widow may be left with insufficient funds to support herself, her partner's affairs may be in disarray, or she may be ostracized or blamed after the death of a loved one.

Suicidality — Among individuals with prolonged grief disorder, suicidal ideation appears to be present in approximately 40 to 60 percent, with a small minority of these patients also exhibiting suicidal behavior [57,58]:

- A community-based sample of bereaved individuals (n = 309) found that suicidal ideation and behavior occurred in more bereaved individuals with than without prolonged grief disorder (37 versus 4 percent) [57]. The risk of suicidality among patients with prolonged grief disorder remained elevated after controlling for potential confounding factors such

as comorbid unipolar major depression and posttraumatic stress disorder, suggesting that suicidal ideation in patients with prolonged grief disorder may be independent of comorbid psychopathology [59-62]. The study also found that the increased risk of suicidal ideation persisted during prospective follow-up four months after baseline assessments.

- In a study of older adult bereaved individuals who lost their spouse within the last two years (n = 130), suicidal ideation occurred more often in individuals with prolonged grief disorder than those without the disorder (57 versus 24 percent) [58].

- A treatment study of patients with prolonged grief disorder (n = 149) found that at baseline, suicidal ideation was reported by 65 percent, and suicide attempts had occurred in 9 percent [63].

Among patients with prolonged grief disorder, suicidal ideation may be more common after death of a loved one by suicide than bereavement due to other causes. A randomized trial for treatment of prolonged grief disorder included patients bereaved by suicide (n = 58), by accidents or homicide (n = 74), or by natural causes (n = 263) [64]. The lifetime prevalence of active suicidal ideation was greater in those with suicide bereavement than bereavement from accidents/homicide and natural causes (43 versus 28 and 22 percent). In addition, those bereaved by suicide endorsed higher levels of impairment, social isolation, subjective alienation, and guilt related to the loss, all of which may contribute to a risk for suicidal ideation and behavior.

Risk factors for suicidal behavior in a treatment study of patients with prolonged grief disorder included longer duration of prolonged grief disorder and more severe symptoms of prolonged grief disorder, depression, and anxiety [63]. In some cases, suicidal behavior in patients with prolonged grief disorder may represent an attempt to join the person who died.

The primary deterrent to suicidal thinking and behavior may be the presence and support of family members [65].

Information about bereavement in the general population and suicidal ideation and behavior is discussed separately. (See "Bereavement and grief in adults: Clinical features", section on 'Suicidality'.)

Adverse consequences — Prolonged grief disorder is associated with adverse consequences that include [1,7,22,57,59,66]:

- Increased use of alcohol and tobacco use
- Onset or worsening of psychiatric disorders

- Functional impairment
- Poor quality of life
- Suicidal thoughts and acts
- General medical illnesses
- Increased mortality

Information about bereavement in the general population and adverse psychiatric and general medical outcomes is discussed separately. (See "Bereavement and grief in adults: Clinical features", section on 'Bereavement'.)

Course of illness — In prolonged grief disorder treatment studies, the average time since the death is two to four years. However, prolonged grief disorder can be diagnosed after six months [67] or one year [68] and it can persist for longer periods [7]. In several studies that identified patients currently suffering from prolonged grief disorder, the average elapsed time since the loss ranged from 10 to 16 years [9,16,17,19,23,69,70]. In a study of individuals who lost loved ones during the Khmer Rouge massacres in Cambodia (n = 775), 14 percent met criteria for prolonged grief disorder approximately 30 years after the loss [25].

Symptoms of prolonged grief disorder may become more intense on the anniversary of the birth and death of the deceased person [7]. In addition, grief triggers can occur at family holidays or other special times such as graduations, marriage, birth of a baby, or the death of another family member.

COMORBIDITY

Psychiatric — Prolonged grief disorder is often accompanied by comorbid psychopathology [25,45,46,71,72], and prolonged grief disorder symptom severity and functional impairment are greater in patients with comorbidities than those without comorbidity [73]. Given that prolonged grief disorder is a relatively new diagnosis, patients with may initially present seeking treatment for a comorbid disorder [47].

In studies of patients seeking treatment for prolonged grief disorder, the prevalence of current comorbid disorders was approximately as follows:

- Unipolar major depression – 50 percent [2,47,57,63,73,74]
- Posttraumatic stress disorder (PTSD) – 30 to 50 percent [2,25,47,57,73-75]
- Anxiety disorders [47,73,76]:

- Generalized anxiety disorder – 20 percent
- Panic disorder – 10 to 20 percent

Separation anxiety disorder and substance use disorders are also sometimes seen with prolonged grief disorder [10,45,77].

The prevalence of major depression and PTSD is greater in bereaved individuals with prolonged grief disorder than those without prolonged grief disorder [57], and greater in prolonged grief disorder than the general community [23].

Patients seeking treatment for prolonged grief disorder sometimes experience multiple concurrent comorbid psychiatric disorders [78,79]. As an example, a treatment study of 206 patients with prolonged grief disorder found that comorbid unipolar major depression and PTSD were both present in 36 percent of patients [73].

Information about bereavement in the general population and comorbid psychopathology is discussed separately. (See "Bereavement and grief in adults: Clinical features", section on 'Associated psychopathology'.)

General medical — Multiple studies suggest that prolonged grief disorder is associated with general medical comorbidity, such as acute coronary syndrome. An observational study enrolled 149 people with no prior history of coronary heart disease, who were hospitalized for acute coronary syndrome; prolonged grief disorder was present in 79 percent [80]. In addition, the analyses found that after controlling for potential confounding factors (age, sex, and cardiovascular risk factors), the severity of prolonged grief disorder symptoms was positively correlated with the occurrence of the acute coronary syndrome between one and four years after the death of a loved one. A separate study found that a range of diseases (eg, upper gastrointestinal conditions) were reported by more patients with prolonged grief disorder than controls [81].

Information about bereavement in the general population and morbidity and mortality from general medical illnesses is discussed separately. (See "Bereavement and grief in adults: Clinical features", section on 'Adverse general medical outcomes'.)

ASSESSMENT

Initial evaluation — The initial evaluation for patients with a possible diagnosis of prolonged grief disorder includes a psychiatric history, mental status examination, general medical history, physical examination, and focused laboratory tests [82,83].

- **History of present illness** – The history is the most important component of the evaluation for diagnosing prolonged grief disorder and is obtained from the patient; in addition, family members and other clinicians can provide useful information. The interview should:

  - Establish the presence, intensity, and chronology of prolonged grief disorder symptoms, as well as information about the relationship to the deceased and the circumstances of the death. Suicidal ideation and behavior should always be assessed. (See 'Signs and symptoms' above and 'Diagnosis' below.)

  - Determine the impact of symptoms upon occupational and interpersonal functioning, including social support and level of engagement in meaningful activities since the death.

  - Ascertain the presence of comorbid conditions such as unipolar major depression, posttraumatic stress disorder, anxiety disorders, and substance use disorders. (See 'Comorbidity' above.)

- **Social history** – The evaluation includes interpersonal, occupational, and financial circumstances; stressors aside from the death; and the context for the clinical presentation. In addition, the social history may identify social isolation and possible sources of support who may be enlisted for treatment, as well as individuals who have been notably unsupportive. Assessment of family functioning may be useful in understanding the context of the presenting disorder and possible benefit of family therapy. (See "Unipolar depression in adults: Family and couples therapy", section on 'Assessment'.)

- **Family history** – Patients should be asked about a family history of depression, psychosis (eg, delusions and hallucinations), and suicide, because family history may confer increased risk for particular disorders or suicide. In addition, other family members may be struggling with the same loss in similar or different ways that may impact the patient.

- **Mental status examination** – The mental status examination supplements the history by assessing features associated with prolonged grief disorder, including alterations in cognition (attention, concentration, and memory), speech, affect, psychomotor activity, and ruminative thought processes. (See "The mental status examination in adults".)

- **General medical history** – The assessment should address all current and significant past general medical conditions, as well as a review of systems and medication use. Adherence to prescribed medical regimens should also be assessed.

- **Physical examination** – Although the benefit of physical examinations in prolonged grief disorder has not been demonstrated, we suggest a screening physical examination, particularly for patients with severe symptoms of prolonged grief disorder and/or prominent somatic symptoms, as well as patients who have or are at risk for chronic medical conditions. More detailed physical examination should be pursued as guided by the history and review of systems.

- **Laboratory evaluation** – The utility of screening laboratory tests has not been demonstrated; nevertheless, we suggest focused tests, particularly for patients with severe symptoms of prolonged grief disorder because these patients often neglect their health and may have undiagnosed medical issues that are clinically actionable. Commonly performed screening laboratory tests include complete blood count, serum chemistry panels, urinalysis (including toxicology when indicated), thyroid-stimulating hormone, and rapid plasma reagin. Neuroimaging studies are reserved for patients whose evaluation suggests an increased likelihood of structural brain disease (eg, focal neurologic signs). Other laboratory evaluations (eg, sleep studies) should be pursued as guided by the history, review of systems, and physical examination.

Suicide risk — All patients with prolonged grief disorder must be queried specifically about suicidal ideation and behavior, including behaviors that are meant to "leave death to chance." Patients may discontinue needed medical treatment and/or take unusual physical risks (eg, crossing streets without watching for oncoming cars) because they wish to die but fear the consequences of suicide or believe it is wrong [63].

If patients acknowledge suicidal ideation or behavior, or provide equivocal responses, clinicians should [84-86]:

- Ask about the specific nature of the ideation, intent, plans, and actions, as well as access to means for suicide and the lethality of those means

- Assess patients for suicide risk factors, including:

  - Prior history and seriousness of suicide attempts

  - Comorbid psychiatric disorders, such as anxiety, depressive, and substance use disorders, as well as psychotic symptoms (eg, delusions or command auditory hallucinations)

  - Family history of suicidal behavior

  - Recent exposure to suicide, such as the deceased loved one

- Current acute stressors
- Level of social support

- Ask about protective factors and reasons for living
- Develop a safety plan (figure 1) for further evaluation and treatment that depends upon the level of risk and may range from continued primary care follow-up alone to outpatient psychiatric or emergency department psychiatric evaluation (see "Suicidal ideation and behavior in adults", section on 'Safety plan')

Additional information about suicidal ideation and behavior, including risk factors, patient evaluation, and management is discussed separately. (See "Suicidal ideation and behavior in adults".)

Screening instruments — Screening bereaved individuals can facilitate diagnosis of prolonged grief disorder. However, there is no evidence that screening improves outcomes and it is not likely that screening alone is beneficial. Studies in unipolar major depression indicate that screening is beneficial only in settings that can provide follow-up to confirm the diagnosis and provide effective treatment. In addition, prolonged grief disorder is not diagnosed until at least 6 to 12 months have elapsed after the loss; while patients with significant acute grief within the first 12 months after the loss may score high on screening instruments, this is not necessarily indicative of future difficulties.

For clinicians who want to screen for prolonged grief disorder, a relatively short screening instrument is the Brief Grief Questionnaire (table 1), which is a five-item, self-report questionnaire with acceptable reliability and validity [30,87]. The questionnaire, which has been used in clinical and community studies, asks about:

- Difficulty accepting the death
- Impaired functioning secondary to grief
- Disturbing images or thoughts of the death
- Avoiding things related to the deceased
- Feeling cut off or distant from people

Responses are rated as follows:

- Not at all – 0
- Somewhat – 1
- A lot – 2

A score ≥4 indicates a positive screen for prolonged grief disorder, and the respondent should be interviewed to establish or rule out the diagnosis of prolonged grief disorder [22,71].

Across different studies, an instrument that has been widely used to screen for prolonged grief disorder is the Inventory of Complicated Grief, which is a 19-item, self-report questionnaire that has good to excellent psychometric properties and takes approximately five minutes to complete (table 2) [55]. The items assess the frequency of emotional, cognitive, and behavioral responses to the death, and are scored on a five-point scale ranging from 0 (never) to 4 (always); total scores range from 0 to 76. A score >25 suggests possible prolonged grief disorder and a score >30 indicates prolonged grief disorder is very likely.

Another self-report measure, which aligns with the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR) criteria (see 'Diagnostic criteria' below), is the 13-item Prolonged Grief Disorder-13-Revised scale, which was validated for assessing prolonged grief disorder symptom severity and DSM-5-TR prolonged grief disorder criteria [88]. The scale requires approximately five minutes to complete. Items are rated from "1 = not at all" to "5 = overwhelmingly." Summed scores range from 10 to 50 and a positive screen is a score ≥30.

Diagnostic instruments — The Structured Clinical Interview for Complicated Grief is a structured, interviewer-administered instrument that is available for diagnosing complicated grief and has good psychometric properties (the diagnostic criteria for complicated grief and prolonged grief disorder overlap considerably) [89]. However, interviewer-administered diagnostic instruments are rarely used in routine clinical practice. Although a structured instrument enables interviewers to clarify ambiguous or contradictory responses, and may help with the differential diagnosis, structured instruments are labor intensive and generally reserved for specialized evaluation, treatment, or research settings.

DIAGNOSIS

Overview — Prolonged grief disorder should be diagnosed according to criteria in the DSM-5-TR [88]. The World Health Organization's International Classification of Diseases-11th Revision (ICD-11) provides a narrative guideline for diagnosing prolonged grief disorder, rather than diagnostic criteria [67]. Nevertheless, the DSM-5-TR criteria and the ICD-11 guideline are similar and likely will identify most of the same individuals.

The evidence indicates that prolonged grief disorder is a unique condition that represents a separate symptom cluster distinct from bereavement-related depressive disorders, anxiety

disorders, and trauma- and stressor-related disorders [1,61,90-95]. The distinction from typical acute grief is primarily related to its persistence over a period beyond that which is expected by the bereaved person's social group. (See 'Differential diagnosis' below.)

Concerns have been raised that formal recognition of prolonged grief disorder as a medical condition will "medicalize" grief and lead clinicians to misdiagnose and incorrectly manage individuals with normal bereavement-related distress [7,27,96]. However, prolonged grief disorder is a continuation of grief beyond the time usually required to integrate a loss, and making a formal diagnosis facilitates the possibility of a life-changing intervention [92]. Clinicians need to recognize and attend to prolonged grief disorder, given that it causes persistent suffering and functional impairment, and is associated with an increased risk of morbidity and mortality [1].

Many patients with prolonged grief disorder are relieved by receiving the correct diagnosis and learning that treatment is available [10]. In a small prospective study of 16 patients who were eventually diagnosed with prolonged grief disorder, 15 (94 percent) initially reported that receiving a diagnosis for their symptoms would provide relief, and all 16 reported that they would be interested in treatment [97].

Diagnostic clues — The presence of prolonged grief disorder is suggested by thoughts, feelings, and behaviors that are normal in bereavement, but indicative of prolonged grief disorder when they are intense, disabling, inconsistent with cultural and religious norms, and persist for at least 6 to 12 months [7,26]. Examples include:

- Difficulty accepting the loss
- Thoughts that focus upon troubling circumstances or consequences of the death, such as the recurrent idea that the death should not have happened when or how it did
- Imagining alternative scenarios to the death (counterfactual thinking)
- The idea that the death should have been prevented by oneself or others
- Pessimism or worries about one's ability to cope without the deceased person (eg, "I can't go on without this person")
- Inability to find purpose or meaning in one's life without the deceased
- Beliefs that one should not enjoy life because the deceased can no longer do so

- Discomfort experiencing positive emotions during at least some periods of the day – Most bereaved people experience these restorative emotions
- Judging one's grief (eg, "I shouldn't grieve so much" or "I need to keep grieving")
- Avoiding reminders that activate intense grief, such as prior shared activities
- Focusing excessively on trying to feel close to the deceased person through sensory stimulation, such as smelling the person's clothes, listening to the person's recorded voice, or looking at pictures
- Difficulty regulating strong emotions

Diagnostic criteria — We suggest diagnosing prolonged grief disorder according to the criteria in the DSM-5-TR, which have demonstrated reliability and validity [39,68,88]. Each of the six primary criteria are required to make the diagnosis:

- Death of someone close to the bereaved individual at least 12 months ago.
- Since the death, at least one of the following symptoms to a clinically significant degree for most days, and for nearly every day during at least the last month:
  - Intense yearning or longing for the deceased person
  - Preoccupation with thoughts or memories of the deceased person
- Since the death, at least three of the following symptoms to a clinically significant degree for most days, and for nearly every day during at least the last month:
  - Disruption of identity (eg, feeling that part of oneself has died)
  - Disbelief about the death
  - Avoiding reminders of the death
  - Emotional pain (eg, sorrow, anger, or bitterness) related to the death
  - Emotional numbness (eg, marked decrease in the intensity of one's emotions), due to the death
  - Feeling that life is meaningless, due to the death
  - Loneliness, due to the death

- Problems resuming relationships and activities (eg, difficulties reconnecting with friends, pursuing interests, and making plans)

- Clinically significant distress or impaired functioning (eg, personal, family, social, educational, or occupational).

- The duration and intensity of the grief response exceeds expected social, cultural, or religious norms for the bereaved individual's social context and culture.

- The symptoms are not the result of another psychiatric disorder (eg, unipolar major depression or posttraumatic stress disorder), a substance (eg, medication or alcohol), or a general medical disorder.

A reasonable alternative to the DSM-5-TR criteria for diagnosing prolonged grief disorder is the narrative guideline included in the ICD-11 [7,67,98]. The guideline is less specific, leaving more room for clinical judgment. In contrast to DSM-5-TR, ICD-11 allows diagnosis of prolonged grief disorder after only six months of symptoms. The clinical features described in the ICD-11 guideline include the following:

- Bereavement following the death of a partner, parent, child, or another close person.

- At least one of the following:

  - Persistent and pervasive longing for the deceased.

  - Persistent preoccupation with the deceased that is accompanied by difficulty accepting the death or by denial of the death, intense emotional pain (eg, sadness, guilt, or anger) or emotional numbness), inability to experience positive emotions, blaming oneself or others, feeling that part of one's self has been lost, and difficulty in engaging in social or other activities.

- The grief response has persisted for an abnormally long period of time following the loss (minimum of six months), exceeding expected social, cultural, or religious norms for the individual's social context and culture. Grief responses for periods longer than six months that are normal for one's cultural context should not be diagnosed as prolonged grief disorder.

- The disturbance significantly impairs important areas of functioning, including personal, family, social, or occupational functioning.

DIFFERENTIAL DIAGNOSIS

The differential diagnosis of prolonged grief disorder includes typical acute grief, bereavement-related major depression, and bereavement-related posttraumatic stress disorder (PTSD) [30]. Several studies have found that prolonged grief disorder is distinct from typical grief as well as other psychiatric disorders, and the differentiation of prolonged grief disorder from these other conditions has been corroborated in different subgroups, such as females and males, and individuals bereaved through violent and nonviolent deaths [99].

Distinguishing prolonged grief disorder from major depression and PTSD requires awareness that these two conditions may be comorbid with prolonged grief disorder (see 'Comorbidity' above). As an example, exposure to violent or sudden losses such as finding a loved one after a suicide can cause PTSD in addition to prolonged grief disorder.

Typical acute grief — Typical acute grief (integrated grief) and prolonged grief disorder share features such as yearning, longing, and preoccupation with thoughts and memories of the deceased, as well as sorrow, anxiety, anger, guilt, and feelings of emptiness. In addition, symptoms of acute grief and prolonged grief disorder may become more intense on the anniversary of the birth and death of the deceased person [7]. However, prolonged grief disorder is distinguished by unrelenting grief symptoms and impaired functioning that persist beyond the time expected by one's social and cultural context, usually thought to be at least 6 to 12 months after the death of a loved one [45].

Prolonged grief disorder entails persistence of responses to the death that are usually relinquished during typical acute grief, including disbelief and/or protest, imagining alternative scenarios to the death (counterfactual thinking), blaming oneself or others, discomfort with grief and its attendant emotional pain, efforts to avoid reminders that activate grief, persistent feelings of intense loneliness and inability to connect with others, survivor guilt, and inability to move forward in life. When persistent, these responses impede adaptation to the loss. By contrast, acute grief is marked by adaptation to the loss, acceptance of its reality, a changed relationship to the deceased, a renewed capacity to thrive with interest in activities and relationships, and the feeling that life has purpose and meaning [100,101]. Acute grief and any associated functional impairment dissipate over a variable length of time, but usually within 6 to 12 months. Grief evolves to a background state that is integrated into the bereaved person's life and can contribute to personal learning and growth.

Additional information about the manifestation of typical acute grief is discussed separately. (See "Bereavement and grief in adults: Clinical features", section on 'Typical acute grief'.)

Unipolar major depression — Bereavement can worsen depression and/or precipitate new episodes of unipolar major depression that may co-occur with prolonged grief disorder (see 'Psychiatric' above). In addition, symptoms such as sadness, guilt, sleep disturbance, social withdrawal, and suicidal thinking and behavior can occur in both prolonged grief disorder and major depression [1,2,53,63]. However, the two disorders differ in that the core symptoms of prolonged grief disorder are yearning, longing, and preoccupation with the deceased, whereas the core symptoms of depression are sadness and loss of interest and pleasure.

Grief symptoms are centered upon the loss of a loved one while depressive symptoms are more general and center on negative feelings about oneself and the world. As an example, sadness in prolonged grief disorder is related to missing the deceased, whereas sadness in depression is pervasive [2]. Ruminations in prolonged grief disorder focus upon the death or the person who died, whereas depressive ruminations involve thoughts of worthlessness. Guilt in prolonged grief disorder is specifically related to survivor guilt or caregiver self-blame pertaining to the deceased or letting the deceased down in some way, as opposed to the more pervasive sense of guilt and worthlessness seen in depression [1]. Suicidal ideation in prolonged grief disorder is focused on not wanting to live, not seeing a promising future without the deceased, or wanting to join the deceased; by contrast, suicidality in depression reflects more general hopelessness, worthlessness, and desperation about changing one's condition.

Other features of prolonged grief disorder not seen in major depression include behaviors enacted to feel close to the deceased, intrusive or preoccupying thoughts of the deceased that sometimes entail pleasant daydreams of alternative scenarios to the death, intense emotions activated by reminders of the loss, and efforts to avoid these reminders [2,45].

Additional information about the clinical features, assessment, and diagnosis of major depression (table 3) is discussed separately. (See "Unipolar depression in adults: Clinical features" and "Unipolar depression in adults: Assessment and diagnosis".)

Posttraumatic stress disorder — Prolonged grief disorder also needs to be differentiated from PTSD among individuals who experience the violent or accidental death of a loved one (ie, a death that qualifies as a traumatic event in the DSM-5) [45]. Both disorders can be characterized by a sense of shock, intrusive images, avoiding stimuli associated with the death, feeling estranged from others, insomnia, and impaired concentration [1,2,45].

However, several differences distinguish PTSD from prolonged grief disorder. The hallmark of PTSD is fear (that the traumatic event will occur again or that the world is unsafe) and horror, whereas the hallmark of grief is yearning and longing (ie, separation distress over the absence of the deceased) [2,45,92,100]. Hypervigilance to threat, excessive startle response, and

nightmares often occur in PTSD, but are generally not seen in prolonged grief disorder. To the extent that hypervigilance occurs in prolonged grief disorder, it is directed toward searching for reminders of the deceased [100]. Nightmares are common in PTSD and rare in prolonged grief disorder. Sadness is less prominent in PTSD than prolonged grief disorder [1,2,10,45,100].

The intrusive thoughts that occur in PTSD involve distressing memories of the traumatic event; by contrast, intrusive thoughts in prolonged grief disorder are focused upon the deceased, and are often positive or comforting. In addition, patients with PTSD avoid fear-inducing stimuli because they feel threatened, whereas avoidance behavior in prolonged grief disorder involves efforts to avert painful sadness and yearning brought about by reminders of the loss and its permanence.

Additional information about the clinical features, assessment, and diagnosis of PTSD (table 4) is discussed separately. (See "Posttraumatic stress disorder in adults: Epidemiology, pathophysiology, clinical features, assessment, and diagnosis".)

INFORMATION FOR PATIENTS

Information for patients about grief and prolonged grief disorder is available in the following graphic that can be printed (table 5) and online at The Center for Prolonged Grief. Information for patients bereaved by suicide is available online at the American Foundation for Suicide Prevention.

SUMMARY

- **Terminology** – Bereavement is the situation in which a loved one has died, and grief is the response to bereavement. Acute grief can be intense and disruptive, but is usually integrated over time. Prolonged grief disorder is a is a unique and recognizable mental disorder marked by unrelenting, intense, and functionally debilitating symptoms that require specific treatment. (See 'Terminology' above and "Prolonged grief disorder in adults: Treatment".)

- **Epidemiology** – The incidence of prolonged grief disorder in the general population is approximately 2 to 5 percent; among the subset of individuals who are bereaved, the estimated prevalence is 10 percent. However, these rates are based upon heterogeneous studies that were conducted prior to the advent of standard diagnostic criteria for prolonged grief disorder. (See 'Epidemiology' above.)

- **Pathogenesis** – The pathogenesis of prolonged grief disorder is not known. However, the neurobiology of prolonged grief disorder may be distinct from that of integrated grief. (See 'Pathogenesis' above.)

- **Clinical features** – The symptoms of prolonged grief disorder include intense, pervasive, and persistent grief manifesting as yearning, longing, or preoccupation with the deceased, as well as emotional pain and impaired functioning. Symptoms last longer than expected by social norms (eg, at least 6 to 12 months after the loss). Suicidal ideation occurs in approximately 40 to 60 percent of patients with a small minority of these patients exhibiting suicidal behavior. Prolonged grief disorder may persist for years or decades after the loss of a loved one, and is associated with increased mortality. (See 'Clinical features' above.)

- **Comorbidity** – Comorbidity in prolonged grief disorder includes unipolar major depression, posttraumatic stress disorder (PTSD), and anxiety disorders, as well as general medical illnesses. (See 'Comorbidity' above.)

- **Assessment** – The initial evaluation for patients with a possible diagnosis of prolonged grief disorder includes a psychiatric history, mental status examination, general medical history, physical examination, and focused laboratory tests. The most important component of the evaluation is the history, which includes information about the relationship to the deceased, the circumstances of the death, subsequent grief symptoms, comorbid psychopathology, and suicidal ideation and behavior, as well as the impact of symptoms upon occupational and interpersonal functioning. (See 'Assessment' above.)

- **Diagnosis** – We suggest diagnosing prolonged grief disorder according to criteria in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR). However, a reasonable alternative is the diagnostic guideline in the World Health Organization's International Classification of Diseases-11th Revision (ICD-11). (See 'Diagnostic criteria' above.)

- **Differential diagnosis** – The differential diagnosis of prolonged grief disorder includes typical acute grief, major depression, and PTSD. (See 'Differential diagnosis' above.)

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