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Commentary on Evidence in Support of a Grief Related Condition as a DSM Diagnosis

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Abstract

The death of a loved one is one of life's greatest stressors. Most bereaved individuals experience a period of acute grief that diminishes in intensity as they adapt to the changes brought about by their loss. Over the past four decades a growing body of research has focused on a form of prolonged grief that is painful and impairing. There is a substantial and growing evidence base supports the validity and significance of a grief-related disorder, including the clinical value of being able to diagnose it and provide effective targeted treatment. ICD-11 will include a new diagnosis of Prolonged Grief Disorder (PGD). DSM-5 called this condition Persistent Complex Bereavement Disorder (PCBD) and included it in Section III, signaling agreement that a diagnosis is warranted while further research is needed to determine the optimal criteria. Given the remaining uncertainties, reading this literature can be confusing. There is inconsistency in naming the condition (including complicated grief as well as PGD and PCBD) and lack of uniformity in identifying it, with respect to the optimal threshold and timeframe for distinguishing it from normal grief. As an introductory commentary for this *Depression and Anxiety* special edition on this form of grief, the authors discuss the history, commonalities, and key areas of variability in

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Conflicts of Interest:

In the past 36 months, Naomi M. Simon reports the following: 1) research grants from the Department of Defense, NIH, PCORI, American Foundation for Suicide Prevention, and Janssen 2) speaking/CME/consulting from Axovant Sciences, Springworks, Praxis Therapeutics, Genomind and Aptinyx, and 3) equity (spouse) from G1 Therapeutics.

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identifying this condition. We review the state of diagnostic criteria for DSM-5 and the current ICD-11 diagnostic guideline, highlighting the clinical relevance of making this diagnosis.

Keywords

grief; diagnosis; complicated grief; persistent grief; prolonged grief; DSM-5; ICD-11

Purpose of this commentary

This special edition of *Depression and Anxiety* focuses on papers addressing bereavement and persistent impairing grief. The current commentary is intended as an anchor to assist readers in understanding this condition and to briefly summarize relevant findings. Our goal is to provide a context for readers to clarify commonalities and differences among variously named and identified entities, and provide an update on the current state of official diagnostic criteria. The commentary begins with a brief discussion of terms and key issues, followed by the nature of usual grief and the clinical persistent form of grief. Next, we focus on the clinical utility of an official diagnosis, including evidence that differentiates this condition from other DSM disorders, as well as availability of simple, reliable assessment tools and well-researched efficacious treatment. We also consider the benefit to harm ratio of establishing an official diagnosis. We describe the use of dimensional as well as categorical assessment approaches and provide a brief summary of the history and current state of diagnostic proposals. Throughout this commentary, we utilize selected references to illustrate work being done in different areas. However, this is not intended to be a systematic review of the field, which would be well beyond the scope of this paper.

Introduction to Key Issues and Terms

There is growing recognition of the need to define a persistent and impairing grief disorder, based upon research supporting the reliability, validity and clinical utility of such a condition. However, any new diagnosis must be considered carefully, to ensure that there is a favorable benefit to harm ratio and that an optimal criteria set is chosen. Additionally, a new grief diagnosis must have a name. As evidence accumulated, so did different names for this condition. Complicated Grief (CG) is the most commonly used term in the literature, mostly defined using a dimensional rating scale. This was replaced for a time with the term Traumatic Grief (TG). More recently, the term Prolonged Grief Disorder (PGD) has become popular, and DSM-5 introduced yet another name, Persistent Complex Bereavement Disorder (American Psychiatric Association, 2013). Different names for and definitions of this condition might confuse readers. Although differences are not large, it can be challenging to know how to understand a series of manuscripts using different definitions and names for the same condition.

We use the term “Complicated Grief” or “CG” in this commentary because we thought it would be confusing to use the different terms interchangeably and CG remains to date the most common term in the literature. We are using the term CG as a generic designation of the condition that is the target of the papers in the special edition. Having a shared name and definition for clinical and academic pursuits is one of the benefits of official diagnostic

criteria. We are not intending to express a preference for officially adopting this name, nor are we intending to privilege a specific proposed criterion set. It is beyond the scope of this commentary to explicate all the details of the different proposals and discuss their pros and cons; instead, a brief overview of core elements of different proposals and their development is provided below for context.

Considering the Nature of Grief and Complicated Grief

Grief can be defined as the response to bereavement. Grief is usually intense and preoccupying for a time after the loss of a loved one. It can include a mix of strong emotions, insistent thoughts, physiological symptoms, and behaviors, including social and spiritual activities related to the deceased. Loss of someone close is widely recognized as a severe stressor. Grief, as the response to such a loss, is often associated with distress, impairment and at times negative health outcomes (e.g., Stroebe, Schut, & Stroebe, 2007). We do not, however, consider this natural response to be a mental health condition. Nor does it usually persist unmitigated for a prolonged period of time. Most bereaved people are resilient and find ways to adapt after loss (Bonanno, Westphal, & Mancini, 2011; Bonanno et al., 2002; Lundorff, Holmgren, Zachariae, Farver-Vestergaard, & O'Connor, 2017).

Grief subsides as the reality of the loss is accepted and a sense of wellbeing is regained. Loss-related thoughts and feelings recede into the background as a bereaved person's focus realigns with goals and relationships in their ongoing life without the person who died. The process of adapting is influenced by many factors including the circumstances of the loss, personal resources, cultural and religious rituals and time expectations, roles, and the availability of supportive others (Shear, Reynolds, Simon, & Zisook, 2017).

The fact that most people adapt, even to very difficult loss, does not preclude less optimal outcomes. A substantial minority of people are not able to adapt to the loss and thus develop complicated grief. Although prevalence estimates are preliminary without official diagnostic criteria, existing data suggests that complicated grief occurs in 10 to 11% of adults bereaved by natural causes (Lundorff et al., 2017). Rates are likely higher after violent losses such as accident, suicide, homicide or disaster (Heeke, Kampisiou, Niemeyer, & Knaevelsrud, 2017; Kristensen, Weisæth, Heir, & Processes, 2012). Complicated Grief is characterized by persistent, clinically significant loss-related distress and impairment. CG often includes suicidal thinking (Mitchell, Kim, Prigerson, Mortimer, & Behavior, 2005), with even higher rates of suicide ideation amongst the suicide bereaved (Molina et al., 2019). Feelings of intense yearning or longing are core symptoms as are preoccupying ruminative thoughts of the deceased (Eisma et al., 2015). There is also considerable emotional pain, expressed as sadness, guilt, anger, anxiety, shame or a feeling of being shocked, stunned, and/or emotionally numb. People with CG typically experience difficulty accepting the death (e.g., a sense of disbelief, protesting its unfairness, imagining alternative scenarios). There may be a profound sense of isolation and loneliness, or a feeling that life is empty or meaningless without the deceased loved one. Avoidance of reminders that the person is gone is common, and may focus on not engaging in activities or friends they shared with their loved one, or on its opposite. They may be averse to doing anything differently than when their loved one was alive. Taken together, CG symptoms often cause substantial functional impairment that

meets the bar for a clinically significant DSM or ICD diagnosis. These symptoms are similar, regardless of which name, definition or timeframe is used, and when using either dimensional or categorical methods of identification.

Clinical Utility of Including a Diagnosis for Complicated Grief

Considering the key purposes of psychiatric diagnosis is a useful exercise. Although there are important research and epidemiology-related purposes for diagnoses, there is general agreement that clinical utility is their main purpose (American Psychiatric Association, 2013; First et al., 2004; International Advisory Group for the Revision of ICD-10, 2011; Reed & Practice, 2010). First et al., (2004) contend that diagnostic criteria should identify a syndrome associated with significant distress and impairment that is uniquely configured, with natural boundaries from other disorders. Diagnosis should be useful in conceptualizing the condition, communicating clinical information, establishing a differential diagnosis, choosing effective treatment, and predicting clinical management needs. In line with these points, we next discuss the CG as a distinct condition, the ability to reliably assess it, the availability of efficacious treatments, and the favorability of the benefit/harm ratio.

CG is a Distinct Condition:

In response to the stress of loss, there is increased risk of a mental or physical disorder that requires treatment. There is evidence for increased rates of major depressive disorder (MDD), anxiety disorders, and posttraumatic stress disorder (PTSD), especially after an unexpected death (Keyes et al., 2014). These conditions can and should be distinguished from complicated grief. Challenges in making these distinctions include overlapping clinical features, neurobiology and risk factors among affective, stress, trauma and loss-related conditions. Studies regularly show high levels of comorbidity across depressive, anxiety and trauma-related conditions and this has spurred transdiagnostic research (American Psychiatric Association, 2013; Casey et al., 2013). However, boundaries from other conditions, remains an important consideration for a new psychiatric diagnosis (First, Reed, Hyman, & Saxena, 2015). Studies have shown that CG has unique characteristics (e.g., Boelen, van de Schoot, van den Hout, de Keijser, & van den Bout, 2010; Lichtenthal, Cruess, & Prigerson, 2004), as well as moderate rates of comorbidity with its nearest neighbors (e.g., Killikelly et al., 2019; Simon et al., 2007).

Although beyond the scope of this commentary to review the many relevant papers, we call attention to several points. CG symptoms load on different factors than depression, PTSD or anxiety in latent variable analyses (Boelen et al., 2010; Boelen & van den Bout, 2005; Golden & Dalgleish, 2010). Similarly, network analysis studies suggest that CG forms a community of symptoms distinct from those of depression and PTSD symptoms (Djelantik, Robinaugh, Kleber, Smid, & Boelen, 2019; Maccallum, Malgaroli, & Bonanno, 2017; Malgaroli, Maccallum, & Bonanno, 2018). CG is closest to major depressive disorder (MDD) and posttraumatic stress disorder (PTSD: e.g., Chiu et al., 2010; Kersting et al., 2009; Simon et al., 2018; Sung et al., 2011), and also is elevated in anxiety disorders (Marques et al., 2013). However, there are some key differences. Most importantly, yearning, a core grief symptom (e.g., see Prigerson et al., 2009), is a unique emotional

experience not seen in either MDD or PTSD (O'Connor & Sussman, 2014; Robinaugh et al., 2016). While overlearned fear is central to PTSD, yearning is the core response to loss. Exposure to trauma occurs in a discrete period of time and is over. By contrast, exposure to loss is ongoing.

The prominence of thoughts and memories of the deceased which typically accompany yearning and longing in CG differs from MDD, in which there is a pervasive dysphoria with deficits in the ability to experience positive emotions. Grief-related avoidance of reminders that the person is gone is also not seen in depression (Baker et al., 2016; Boelen, van den Hout, & van den Bout, 2008; Shear, 2010). CG also differs from MDD in differential response to treatment (Shear, Frank, Houck, & Reynolds, 2005; Shear et al., 2016; Shear et al., 2014; Simon et al., 2007). DSM-5 includes helpful guidance on differentiating acute grief from depression in the section explaining the elimination of the bereavement exclusion.

CG and Its Symptoms Can be Reliably Assessed in Practice:

There is substantial evidence that associated and core CG symptoms can be reliably assessed with validated measures and development of such measures is continuing. The Texas Revised Inventory of Grief (TRIG: Faschingbauer, Devaul, & Zisook, 1977) was developed in the 1970's and characterizes normal grief. Supporting the premise that CG is on a continuum with normal grief, scores on this instrument correlate highly with scores on measures targeting CG (Melhem et al., 2004). In 1995, Prigerson and colleagues introduced the 19-item self-report Inventory of Complicated Grief (ICG: Prigerson et al., 1995) which, along with its various revisions such as the PG-13 (Morina, Von Lersner, & Prigerson, 2011), have been widely used worldwide. The top 20% of their original ICG sample scored > 25 and endorsed significantly higher scores on an impairment measure; this cut score was recommended as indicative of complicated grief (Prigerson et al., 1995). The *American Psychological Association* website endorses this recommendation (American Psychological Association). Researchers continue to publish study results using this method of identifying CG (Milic et al., 2019; Pérez et al., 2017; Thimm, Davidsen, Elsness, & Vara, 2019). A structured clinical interview also exists as a diagnostic instrument, and has demonstrated good test–retest, and inter-rater reliability (Bui et al., 2015). Multiple validated self-report measures are available that focus on specific aspects of CG. For example, the Utrecht Grief Rumination Scale (Eisma et al., 2014), the Traumatic Grief Inventory-Self Report (Boelen, Djelantik, de Keijser, Lenferink, & Smid, 2018), as well as measures of relevant constructs such as yearning (Yearning in Situations of Loss: O'Connor & Sussman, 2014), grief-related avoidance (Grief Related Avoidance Questionnaire: Baker et al., 2016), and grief-related cognitions (Typical Beliefs Questionnaire: Skritskaya et al., 2017). Validation of measures of core symptoms across gender, cultures and races, as well as loss by illness or violent means (Boelen & Hoijtink, 2009; Zisook et al., 2018), further support the reliability of a measurable CG construct. These and other instruments as well as the ICD-11 guidelines are currently available for use by clinicians to support assessment and clinical monitoring in practice, even without a formal DSM diagnosis.

There is Evidence for Efficacy of Specific Targeted Treatment:

For those treating patients in practice, perhaps the most important evidence for the value and urgency of CG diagnosis is the well-replicated finding that adults with this condition show a strong and specific response to CG-targeted treatment (Shear et al., 2005; Shear et al., 2016; Shear et al., 2014), including its administration in a group (Supiano & Luptak, 2013). Studies by Boelen et al (2007) and Bryant et al (2014) further support the effectiveness of exposure to the story of the death, as well as long-term efficacy (Boelen, de Keijser, van den Hout, & van den Bout, 2007; Bryant et al., 2014; Bryant et al., 2017). Internet therapies targeting CG are also available to disseminate these types of approaches (Kersting et al., 2013; Wagner, Knaevelsrud, & Maercker, 2006). Even without an official diagnosis, treatment development continues (e.g., Kealy et al., 2017; Papa, Sewell, Garrison-Diehn, & Rummel, 2013; Rosner, Bartl, Pfoh, Kotoučová, & Hagl, 2015; Rosner, Pfoh, Kotoučová, & Hagl, 2014; Rosner, Rimane, Vogel, Rau, & Hagl, 2018; Supiano & Luptak, 2013; van Denderen, de Keijser, Stewart, & Boelen, 2018).

Benefit to Harm Ratio is favorable:

It is important to consider the benefit to harm ratio of establishing a CG diagnosis. Reports indicate that some clinicians fear that a CG diagnosis would medicalize or pathologize a natural human response. There is concern that such a diagnosis could be stigmatizing and/or lead to unnecessary intervention. (Dietl, Wagner, & Fydrich, 2018; Eisma & Lenferink, 2018). A grief diagnosis will almost certainly have some associated stigma (Eisma, 2018; Eisma, Te Riele, Overgaauw, & Doering, 2019) as this is an unfortunate but unavoidable consequence of all psychiatric disorders. On the other hand, there are important benefits of official diagnosis, and one study found the majority of mental health clinicians favor its inclusion (Dodd, Guerin, Delaney, & Dodd, 2019). Another study found that providing information about CG to clinicians was clinically useful and did not increase pathologizing normal grief (Lichtenthal et al., 2018). Untreated, patients with CG are at increased risk for negative outcomes such as suicide, mental and physical comorbidities, and impaired functioning and quality of life (Boelen & Prigerson, 2007; Stroebe et al., 2007). Patients benefit from naming their experience, learning about the condition, knowing they’re not alone, and, especially, from effective intervention (Johnson et al., 2009). Diagnostic information alongside psychoeducation can help ensure that friends and family are best able to be supportive. Open discussion and advocacy can also help relieve the suffering of those in need who are afraid to come forward. On balance, the benefits of diagnosis appear to outweigh potential harm of stigma or costs of treatment. Along with many colleagues, we are supporting ongoing work to finalize a DSM diagnosis.

A Brief History of Diagnostic Criteria Proposals

Over the last three decades, three specific diagnostic criteria proposals have been presented for consideration of inclusion in the DSM (Horowitz, Bonanno, & Holen, 1993; Prigerson et al., 2009; Shear et al., 2011). These proposals were also reviewed by the ICD-11 workgroup on trauma and related disorders. Horowitz and colleagues (1993) first proposed inclusion of “Pathological Grief” in DSM-IV. After the proposal was rejected because of a need for more research, this group conducted the first criteria development study using a sample recruited

by newspaper advertisement of 70 spousally-bereaved individuals who experienced a loss between the ages of 21 and 55. Thirty grief symptoms were assessed and used to develop a diagnostic algorithm for Complicated Grief Disorder (Horowitz et al., 1997) that included a requirement for 3 of 7 criteria, including two intrusion symptoms, two avoidance/denial symptoms and three symptoms indicating failure to adapt (e.g., inability to resume responsibilities at home or work) at least 14 months after loss.

Next, Prigerson, Shear et al (1999) began development of a set of diagnostic criteria that were iterated over the ensuing decade as traumatic grief (Jacobs, 2000; Prigerson et al., 1999), complicated grief (Lichtenthal et al., 2004), and eventually Prolonged Grief Disorder (Prigerson, Horowitz et al 2009). The latter criteria were finalized using data from a community sample of 291 bereaved people, the great majority of whom were older widows interviewed 0– 6, 6–12 and 12–24 months post-loss. The process to establish the PGD criteria used sophisticated sampling and statistical methodology. The resulting proposal required yearning as the sole gateway symptom with an additional 5 of 9 associated symptoms and associated impairment present after at least 6 months.

A third diagnostic criteria proposal (Shear et al., 2011) was based on analyses of a clinical data set. Simon and colleagues (Simon et al., 2011) analyzed a clinical data set including 782 bereaved individuals most of whom presented for treatment of mood, anxiety or grief-related clinical symptoms. The sample included 288 grief cases who experienced a death at least 6 months earlier, endorsed an Inventory of Complicated Grief (Prigerson et al., 1995) score ≥30, and underwent a clinical interview that confirmed grief as the primary clinical problem. With input from clinical experts, results were used to develop a criteria set for “Complicated Grief” (CG: Shear et al., 2011). A gateway symptom could be met by any of four symptoms indicating yearning or preoccupation with the deceased. Endorsement of at least two additional symptoms from a list representing the remaining clusters, with associated distress or impairment was also required.

The Current State of Official Diagnostic Criteria in ICD-11 and DSM-5

The World Health Organization’s ICD-11 includes Prolonged Grief Disorder as a codable diagnosis (Killikelly & Maercker, 2017; Maercker et al., 2013; World Health Organization). ICD-11 guidelines for diagnosis are simple and flexible. Their structure is prototypic, without a clear requirement for a specified algorithm and specific symptoms. A prototype matching approach is generally preferred by the clinicians who are target users of the ICD-11 guideline. Although past efforts at improving official diagnoses focused on improving the specification and reliability of criteria, the current revision shifted to prioritizing improvements in clinical utility (First et al., 2015; International Advisory Group for the Revision of ICD-10, 2011). This decision was responsive to observations that operationalized criteria tended to be too long and complicated (Hyman, 2007; Keeley et al., 2016; Maj, 2015; Reed, 2010) to be useful in clinical practice (First et al., 2019).

The ICD-11 guideline is flexible. It can be used in a way that fits closely the stricter PGD criteria (Maciejewski et al., 2016) and also in a way that fits the complicated grief criteria (Mauro et al., 2019; Cozza et al., 2019). Its structure focuses on core symptoms of longing

and/or persistent preoccupation with the deceased, as well as additional symptoms of intense emotional pain. A list of possible indicators of emotional pain is included. Additionally clinicians are instructed to look for significant psychosocial impairment, for a minimum of 6 months, assuring they are beyond the expected sociocultural norms for the individual.

The DSM-5 workgroup also reviewed proposals for this condition. Typically, such workgroups obtain a proposal from the field and modify the language and/or other elements to finalize a criteria set. However, in this case there were two proposals (Prigerson et al., 2009; Shear et al., 2011). While the proposals were similar in many ways, there were differences in the symptom configuration and threshold that the committee could not resolve. Instead, they used the name Persistent Complex Bereavement Disorder and created a new, provisional, criteria set and algorithm that includes four options for a gateway symptom and require at least 6 of 12 possible associated symptoms drawn from two separate symptom lists. The criteria must be met for at least 12 months after the loss. Because the criteria were untested, they placed this condition in Section 3 – disorders in need of further research. PCBD is officially codable as a subtype of Other Trauma- and Stressor-Related Disorders in the section on Trauma and Related Disorders (American Psychiatric Association, 2013). While PCBD was a step forward, the important work of establishing official diagnostic criteria for DSM-5.1 remains ongoing.

Summary and Future Directions

CG meets the DSM-5 definition of a mental disorder: “a… clinically significant disturbance in an individual’s cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning” that is “usually associated with significant distress or disability in social, occupational, or other important activities.” Its prevalence is estimated at about 10% for those bereaved by illness and may be at least twice that rate following violent death. Validated clinician- and patient-rated assessment instruments are available, as is targeted efficacious treatment. Such treatment is significantly more effective than treatment for depression, which has generally been weak or ineffective in reducing grief symptoms. While some of the details remain to be finalized by the APA’s DSM-5 committees, such as the number of associated symptoms, their wording, the optimal severity, and the temporal (6 or 12 months) threshold, there is strong evidence to support clinical relevance of this condition and a favorable benefit to harm ratio. Important future research directions to better characterize the condition include identifying the underlying neurobiology and other objective biomarkers, RDoC transdiagnostic approaches to the study of loss, as well as machine learning, longitudinal trajectories, and complex network approaches to the study of loss. As exemplified by the excellent contributions in this special issue of *Depression and Anxiety*, ongoing research will undoubtedly continue to inform the field and help refine the diagnosis and treatment of this condition.

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