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COMPLICATED GRIEF AND RELATED BEREAVEMENT ISSUES FOR DSM-5

M. Katherine Shear¹, Naomi Simon², Melanie Wall, Sidney Zisook³, Robert Neimeyer⁴,
Naihua Duan⁵, Charles Reynolds⁶, Barry Lebowitz⁷, Sharon Sung⁸, Angela Ghesquiere⁹,
Bonnie Gorscak¹⁰, Paula Clayton¹¹, Masaya Ito¹², Satomi Nakajima¹³, Takako Konishi¹⁴,
Nadine Melhem¹⁵, Kathleen Meert¹⁶, Miriam Schiff¹⁷, Mary-Frances O'Connor¹⁸, Michael
First¹⁹, Jitender Sareen²⁰, James Bolton²¹, Natalia Skritskaya²², Anthony D. Mancini²³,
and Aparna Keshaviah²⁴

¹ Columbia University School of Social Work and Department of Psychiatry, Columbia University College of Physicians and Surgeons, New York, New York

² Center for Anxiety and Traumatic Stress Disorders and Complicated Grief Program, Massachusetts General Hospital, Boston, Massachusetts

³ Department of Psychiatry, University of California, San Diego and Veterans Affairs San Diego Health Care System, La Jolla, California

⁴ Department of Psychology, University of Memphis, Memphis, Tennessee

⁵ Departments of Biostatistics and Psychiatry at Columbia University, and Director and Research Scientist in the Division of Biostatistics and Data Coordination at New York State Psychiatric Institute, New York, New York

⁶ Department of Psychiatry, University of Pittsburgh School of Medicine and Department of Community and Behavioral Health Science, University of Pittsburgh Graduate School of Public Health, Western Psychiatric Institute and Clinic, Pittsburgh, Pennsylvania

⁷ Department of Psychiatry, University of California, San Diego, La Jolla, California

⁸ Center for Anxiety and Traumatic Stress Disorders and Complicated Grief Program, Massachusetts General Hospital, Boston, Massachusetts

⁹ Columbia University School of Social Work, New York, New York

¹⁰ Clinical Supervisor, NIMH grant no. R01MH085288, Pittsburgh, Pennsylvania

¹¹ American Foundation for Suicide Prevention, New York, New York

¹² Research Fellow of the Japan Society for the Promotion of Science, and Department of Adult Mental Health, National Institute of Mental Health, National Center of Neurology and Psychiatry, Tokyo, Japan

¹³ Department of Adult Mental Health, National Institute of Mental Health, National Center of Neurology and Psychiatry, Tokyo, Japan

¹⁴ Department of Human Studies, Musashino University, Tokyo, Japan

¹⁵ University of Pittsburgh School of Medicine, Western Psychiatric Institute and Clinic, Pittsburgh, Pennsylvania

- ¹⁶ Department of Pediatrics, Wayne State University School of Medicine, Detroit, Michigan
- ¹⁷ Paul Baerwald School of Social Work, Hebrew University, Mount Scopus, Jerusalem, Israel
- ¹⁸ Cousins Center for Psychoneuroimmunology, Semel Institute for Neuroscience and Human Behavior, University of California, Los Angeles
- ¹⁹ Columbia University Department of Psychiatry, New York State Psychiatric Institute, New York, New York
- ²⁰ University of Manitoba, Winnipeg, Manitoba, Canada
- ²¹ University of Manitoba, Winnipeg, Manitoba, Canada
- ²² School of Social Work, Columbia University, New York, New York
- ²³ Department of Psychology, Pace University, Pleasantville, New York
- ²⁴ Department of Psychiatry, Massachusetts General Hospital, Boston, Massachusetts

Abstract

Bereavement is a severe stressor that typically incites painful and debilitating symptoms of acute grief that commonly progresses to restoration of a satisfactory, if changed, life. Normally grief does not need clinical intervention. However, sometimes acute grief can gain a foothold and become a chronic debilitating condition called complicated grief. Moreover, the stress caused by bereavement, like other stressors, can increase the likelihood of onset or worsening of other physical or mental disorders. Hence some bereaved people need to be diagnosed and treated. A clinician evaluating a bereaved person is at risk for both over- and under-diagnosis, either pathologizing a normal condition or neglecting to treat an impairing disorder. The authors of DSM IV focused primarily on the problem of over-diagnosis, and omitted complicated grief because of insufficient evidence. We revisit bereavement considerations in light of new research findings. This paper focuses primarily on a discussion of possible inclusion of a new diagnosis and dimensional assessment of complicated grief. We also discuss modifications in the bereavement V code and refinement of bereavement exclusions in major depression and other disorders.

Keywords

Complicated grief; DSM-5; diagnostic criteria; dimensional assessment; stress response disorder

INTRODUCTION

This paper considers whether complicated grief (CG) meets the criteria for a mental disorder for which treatment is appropriate. Acute grief is a normal response to loss with symptoms that should not be pathologized. Psychiatrists have long understood that grief should not be treated as pathological. Nearly a century ago Freud wrote, "...although mourning involves grave departures from the normal attitude toward life, it never occurs to us to regard it as a pathological condition and to refer it to a medical treatment. We rely on its being overcome after a certain lapse of time, and we look upon any interference with it as useless or even harmful"[1] (p. 243). Research has proved Freud largely correct[2–5] but not entirely. It is now clear that grief can be complicated, much as wound healing can be complicated, such that intensity of symptoms is heightened and their duration prolonged.

Although refraining from unwarranted diagnosis is important in evaluating a bereaved person, the need for treatment must also be considered. Bereavement is a severe stressor that can trigger the onset of a physical or mental disorder. Clinicians need to recognize and treat

those disorders when present and a cause of significant morbidity or mortality. Untreated illness potentially interferes with natural healing and this is one pathway to the development of complicated grief. For example, major depression, post-traumatic stress disorder and sleep disorders often occur and need treatment.

DSM-5 needs to provide guidance regarding how to recognize normal grief and when to diagnose complicated grief or another mental disorder. This paper reviews research that informs these decisions. The main focus is on whether complicated grief should be included as a new diagnostic category and as a cross cutting dimensional assessment. In addition, we briefly discuss bereavement considerations in other disorders and suggest that the Bereavement V code might be used to provide information about normal grief

SEARCH METHODS

A literature search was conducted using keywords: grief, bereavement, complicated grief, prolonged grief, traumatic grief and unresolved grief in PubMed and PsycINFO databases. There was no time limit for published articles. The search included several edited books on bereavement and grief. We further scrutinized references of published papers and chapters. We examined the DSM III, III-R, IV and IV-TR and related documents describing bereavement exclusions. We include some data analyses from a study that is submitted as a companion manuscript.

DOES COMPLICATED GRIEF (CG) MEET CRITERIA PROPOSED DSM 5 CRITERIA FOR A NEW DISORDER?

A number of studies suggest that most people experience acute grief symptoms that attenuate naturally over a period of time.[5–9] The intensity of acute grief and the period of time over which it occurs are variable, depending upon the closeness of the relationship to the deceased and circumstances of the loss (e.g. the age of the deceased, degree of prior decline and anticipation of the death, the comfort and peacefulness of the person's last days and final moments, etc). Still, studies show that for most people grief intensity is fairly low by a period of about 6 months. This does not imply that grief is completed or resolved, but rather than it has become better integrated, and is no longer stands in the way of ongoing life.

It is also clear that there is a subgroup of individuals whose grief symptoms are more intense and persistent.[6–10] Horowitz et.al. [11–13] suggested that a syndrome of complicated grief (CG) be included in the DSM. They led an initiative, supported by others[14;15] to include CG as a stress response syndrome in DSM IV; however, it was ultimately determined that the evidence was insufficient to warrant its inclusion. Horowitz obtained additional evidence for a CG diagnosis and proposed a criteria set.[16] Since that time evidence supporting the existence of a complicated grief syndrome continues to grow with studies using valid, reliable ratings scales, most commonly a 19-item rating scale called the Inventory of Complicated Grief[17;18] or one of a number of variants of this scale[19;20] or the Core Bereavement Items.[21–23] In agreement with others[17] we believe it is appropriate to again raise the issue of including CG as a new category in DSM-5. Stein and colleagues proposed a list of 10 criteria for the definition of mental disorder building on the definition used in DSM IV[24]. We next consider CG with respect to each of these 10 criteria.

A. A behavioral or psychological syndrome that occurs in an individual—CG is a recognizable syndrome that can be reliably identified with several rating scales, including those mentioned above. The concept is that complications derail or impede healing after loss and lead to a period of prolonged and intensified acute grief. The latter include symptoms of

strong yearning for the person who died, frequent thoughts or images of the deceased person, feelings of intense loneliness or emptiness and a feeling that life without this person has no purpose or meaning. Complications also lead to dysfunctional thoughts, maladaptive behaviors and emotion dysregulation such as troubling ruminations about circumstances or consequences of the death, persistent feelings of shock, disbelief or anger about the death, feelings of estrangement from other people and changes in behavior focused on excessive avoidance of reminders of the loss or the opposite, excessive proximity seeking to try to feel closer to the deceased, sometimes focused on wishes to die or suicidal behavior .

Consequences are clinically significant distress or disability: CG is associated with clinically significant distress and impairment including impairment in work and social functioning,[25–30] [31–38] sleep disturbance,[39–42] disruption in daily activities,[43] suicidal thinking and behavior,[44–48] increased use of tobacco and alcohol,[17;42] and impairment in relationship functioning.[42] CG is also likely to affect the course of other disorders. For example, among people with bipolar disorder, the occurrence of CG is associated with more panic disorder, greater suicidality[32] and greater sleep disturbance. [39]

B. Not merely an expectable response to a common stressor—Acute grief is the expectable response to loss of someone very close. CG is an aberrant response that occurs in a minority of people following the loss of a loved one. Studies suggest that CG occurs in about 10% of bereaved people overall,[17;23] with higher rates among individuals bereaved by disaster[37;49;50] or violent death[51–55] and higher among parents who lose children. [56–58] This syndrome leads to considerable functional impairment, beyond that accounted for by any comorbid depression, PTSD and other anxiety disorders.[27;28;31;33;38] CG has been documented in bereaved relatives of ICU patients,[59;60] terminal cancer patients[61] and palliative care populations,[62] people bereaved by disaster,[20;37;49;63] parents bereaved of children,[56;57;64] bereaved people with intellectual disabilities,[65] bereaved psychiatric outpatients,[66;67] bipolar disorder patients,[32] suicide and homicide survivors, [44;54;68] and in bereaved children and adolescents.[34;69] CG is seen across cultures within the United States[35;70] and in other countries in Western Europe,[19;71–76],as well as Iran,[50] Bosnia,[22] Kosovo[77], Pakistan,[78] Turkey,[79] Rwanda,[80] China,[61;81] and Japan.[82–84]

C. Reflects an underlying psychobiological dysfunction—CG entails harmful dysfunction in that a normal healing process has been derailed. People with CG have complicating symptoms or disorders that change the expected response to bereavement. Many ruminate over various concerns related to the death,[42;85] cannot make sense of the loss,[52;56] catastrophically misinterpret aspects of the loss[85–87] including their own reactions,[86] and avoid reminders of the loss.[33] As a consequence, acute grief symptoms are inordinately prolonged. Compared to normal grief, CG is associated with prolonged distress and disability, negative health outcomes and suicidality. Risk factors include female sex,[37;49] a history of mood disorder,[31;88] low perceived social support,[89] insecure attachment style,[90–94] increased stress, [89] positive caregiving experience with the deceased,[61;62;95;96] cognitions during bereavement,[86;97] pessimistic temperament and personality correlates [98;99] and psychobiological findings reviewed above. Common occurrence of lifetime comorbidity of mood and anxiety disorders suggests common underlying vulnerability.

D. Not solely a result of social deviance or conflicts with society—Cultural and religious factors need to be taken into consideration when making a diagnosis of CG, as they can play a major role in determining the parameters of normal grief for a particular

individual functioning within a particular cultural and religious context. Nevertheless, as cited above, available evidence suggests that CG occurs across cultures that have different views of death and loss and different bereavement rituals. Inclusion of CG in DSM-5 would stimulate research to further elucidate the role of cultural factors.

E. Has diagnostic validators, e.g. prognosis, psychobiology, treatment response—There is evidence for diagnostic validity of CG. While more work is needed to understand the underlying biology of CG, there are a number of studies supporting psychobiological dysfunction. A brain imaging study showed activation of the nucleus accumbens on exposure to cues of the deceased in complicated but not normal grievers. [100] CG was associated with an MAO-A variant in patients with major depression.[101] Several studies showed deficits in specific autobiographical memory functions[102–104] and deficits in means-end problem solving among CG patients.[105] A study of heart rate response during discussion of a loss showed reduced heart rate correlated with CG severity in contrast to increased heart rate which correlated with PTSD.[38]

CG symptoms manifest a chronic persistent course and show little response to nortriptyline[106] or bupropion[107] in open pilot studies, and little response to nortriptyline or interpersonal psychotherapy in a randomized controlled trial.[108] A report of 4 patients shows good response to serotonin-active medication[109] and the first randomized controlled trial of serotonin active antidepressants is underway by 5 of the co-authors of this paper. There is growing evidence supporting efficacy a CG-targeted psychotherapy. [28;110;111]

F. Clinical utility, e.g. better assessment and treatment—In part due to omission of CG in DSM IV, CG appears to be rarely diagnosed in the community. In our treatment studies some people with this condition report they were told their grief is normal. Others were misdiagnosed as having a primary major depressive episode or anxiety disorder. A person with CG may be treated with medication for depression that has been found to have insufficient effect on CG symptoms.[106] Many patients have been on treatment-seeking odysseys for years after the death of a loved one, receiving little help. Our data from 243 individuals seeking treatment for complicated grief in Pittsburgh reveals that 206 (85%) had previously sought treatment for grief. The majority had tried at least one medication and at least one form of counseling. Many had made multiple attempts to get help. Some had been told they were coping as well as could be expected because the loss was very difficult. This type of reassurance was provided even when the bereaved person's life had come to a halt and years had passed since the death.

G. Differentiation from Nearest Neighbors—Because new disorders should be created only when necessary, it is important to consider whether CG can be incorporated into an existing diagnosis, in particular major depression or PTSD. CG resembles depression in that both include symptoms such as sadness, crying, sleep disturbance and suicidal thinking. Is CG best considered a form of major depression? One study found that everyone with CG met current criteria for MDD.[80] However, most research, including clinical studies[27;31;49;88] have found that only about 50–60% of CG samples, meet depression criteria and important differences between CG and MDD exist.

Intense yearning or longing for the deceased is common in CG. There are strong feelings of wanting to be reunited with the lost loved one, associated with behaviors to feel close to the deceased, frequent intrusive or preoccupying thoughts of the deceased and efforts to avoid experiences that trigger reminders of the loss. Yearning in complicated grief appears to be associated with activation of dopamine circuitry.[100] By contrast, in major depression there is reduced capacity for activation of reward pathways.[112–114] Additionally, guilt, when

present in CG, is specific to the death, whereas with depression guilt is usually pervasive and multifaceted.[115] Sleep disturbance is associated with REM sleep abnormalities in depression but not in CG.[41] Clinical experience suggests suicidality in CG is commonly based on imagined reunion with the deceased person, whereas depressed suicidal people tend to report pervasive hopelessness. Factor analysis shows depression and CG load on separate factors.[19;116–118] CG symptoms show little response to interpersonal psychotherapy, a well studied treatment for depression[108;110;111] and medication studies suggest that improvement in depression can occur with only modest changes in CG symptoms.[106;108] Overall, while symptoms can overlap, there is strong evidence that CG is distinct from major depression.

Could CG be included considered a form of chronic PTSD? Experiencing the death of a loved one is a life event that meets the trauma criterion of observing or learning of death. People with CG describe intrusive images of the deceased loved one, engage in avoidance behavior and feel estranged from others. Many report sleep disturbance or difficulty concentrating. At least one study suggests CG might be best conceptualized under the PTSD category.[119] However, confrontation with physical danger is fundamentally different from losing a sustaining relationship, and CG symptoms differ correspondingly from those of PTSD. Moreover most people with CG do not meet criteria for PTSD.[31;34;38;49;88]

Physical trauma represents one or more events contained in space and time that threaten physical harm, increasing fear and hypervigilance. With the exception of situations entailing recurrent exposure to danger (e.g. combat, domestic abuse), actual threat is markedly reduced after the event is over. An adaptive response requires relearning a sense of safety in order to ensure reasonably accurate ongoing evaluation of threat. Bereavement entails permanent loss of something desirable and sustaining and initiates a pervasive and prolonged change in circumstances. Access to the deceased is gone forever. The bereaved person can no longer obtain assistance with difficulties or encouragement and support in facing challenging new endeavors. Loss of a loved one deprives a person of the ongoing sense of wellbeing derived from providing sensitive responsive caregiving.[120] An adaptive response entails understanding the finality and consequences of the loss and redefining life goals and plans in the absence of the loved one.

There are corresponding differences in symptoms of PTSD and CG. The hallmark of PTSD is fear. The hallmark of CG is sadness and yearning. CG and PTSD do share symptoms of disruptive intrusive thoughts and avoidance. However, people with PTSD re-experience thoughts and images of the traumatic event while people with CG experience intrusive images and preoccupation with the deceased person. In PTSD, avoidance is used to prevent recurrence of danger and in CG to avert painful thoughts or feelings related to the loss. Hyperarousal in CG is related to loss of interpersonal regulators,[121–123] rather than hypervigilance to threat. CG differs from both depression and anxiety disorders using factor analyses and other indicators.[17;19;117;118;124] On balance it appears that CG is different from PTSD.

Another possibility would be to use the category of adjustment disorder to diagnose CG. A diagnosis of adjustment disorder is made when response to a stressor is unusually intense or prolonged. By definition, CG meets this description. However, adjustment disorder is reserved for a disparate group of symptoms that do not fit elsewhere. Since there are no specific symptom patterns included in the operationalized criteria for adjustment disorder, it is difficult to study. There is a risk that clinicians would not recognize that CG is a discrete syndrome recognizable across different cultures and different bereavement circumstances. An important reason for adding a CG diagnosis is to provide standard criteria for clinicians and researchers. It makes more sense for CG to be a new diagnostic category.

H. Potential Benefits Outweigh Potential Harm—Potential harm from the diagnosis of CG is primarily related to labeling and stigma. It is important not to stigmatize or pathologize a normal human phenomenon, and this is an important consideration. Grief manifests differently in every person and categorizing symptoms can be difficult. However, CG is much more intense, persistent and debilitating than usual grief and it occurs in a small minority of bereaved people. There is no question that mental disorders remain stigmatized. Despite this, in our experience, and according to Johnson and colleagues,[125] many people feel relief when their problem is named and efficacious treatment is described. The potential benefit of creating a new diagnosis in order to identify individuals who require clinical attention appears to outweigh the potential harm as long as the diagnosis is applied appropriately.

DIAGNOSTIC CRITERIA

Existing data provide strong support for CG as a new category in DSM5, yet most of this work uses a version of the Inventory of Complicated Grief (ICG)[126] or a similar dimensional measure that does not directly inform which subset of symptoms and diagnostic threshold can best be used to define caseness. Principles guiding revisions in DSM5 as outlined on the website (<http://www.dsm5.org/>) include, “The highest priority is ‘clinical utility’ – that is, making the manual useful to clinicians diagnosing and treating people with mental disorders.” Following this mandate, criteria for CG should help clinicians discriminate people with CG from those with and without other psychiatric disorders who do not have this condition. Criteria should also help guide the choice of interventions and outcome assessment.

A number of criteria sets have been proposed for CG.[12;16–18;127–130] The most recent of these is Prigerson et.al. (2009).[17] The sample from which these criteria were derived is not a clinical one, was relatively small (n=291) and included almost exclusively older (average age 62) white (95%) widows (84%), with 60% educated beyond high school and not necessarily generalizable to people with CG who are younger, less educated, from diverse backgrounds and bereaved of other close friends or relatives. Therefore it is only partially informative for deriving clinically useful criteria. Moreover, only 28 study participants were judged to have prolonged grief disorder (PGD, the term used by this group for CG). This small number greatly limits the ability to explore any potentially informative symptom patterns for determining diagnostic criteria. The methodology used to derive criteria was also problematic. Data used were from study subjects bereaved from 0–6 or 6–12 months, yet the authors propose that PGD should not be diagnosed before six months, and others have judged it advisable to wait 1 year. It is questionable whether CG criteria should be derived using data from individuals considered ineligible for the diagnosis. Analyses began with a pre-selected list of 22 of the 39 ICG-R symptoms and no rationale is provided for which symptoms are excluded. Also of note, the ICG-R does not include several symptoms that have been associated with CG and that should be considered as possible criteria, e.g. rumination, physical reactions to the death and suicidality. The final proposed criteria set was derived empirically using item response theory (IRT) followed by an exhaustive subset analysis. Yearning is proposed as a necessary symptom (Criterion B) but it is not clear how and why this decision was made.

Item response theory (IRT) modeling has become a commonly used strategy in assessment research but its validity is based on an initial assumption that the attribute being measured is best represented as a single factor. Such unidimensionality is usual in a group of people with a wide range of scores on an attribute e.g. many who are asymptomatic as well as people exhibiting widely varying levels of symptoms. However, for the purpose of developing criteria, we are particularly interested in item performance among the subgroup of

individuals at the high end of a trait, in this case CG. If multiple dimensions or factors emerge (i.e. certain subgroups of symptoms co-occur more commonly than others), unidimensional IRT (which assumes one single underlying dimension) is not the best approach to understanding item performance. As we explain in a companion paper (Submitted to *Depression and Anxiety* by Naomi Simon, et al.) factor analysis of the ICG in people with high scores shows multiple factors. Therefore, we believe further analyses are needed to refine our thinking about criteria that will optimally identify individuals with CG.

Briefly, we administered the Inventory of Complicated Grief (ICG)[126] to a group of bereaved healthy controls with no psychiatric disorder (n=95), as well as to patients diagnosed as having either a mood or anxiety disorder (n=369), and to patients presenting for treatment of CG (n=318). These samples were recruited under research protocols at Massachusetts General Hospital, and NIMH-funded studies at the University of Pittsburgh (MH060783) and Columbia University (MH070741), and are well characterized, including structured diagnostic assessment by certified experienced clinical raters. Most (304 out of 318) of the participants who self-identified as having CG, had one or more clinical interviews for CG as well as a staffing review of the CG symptoms and other diagnoses. This sample of clinically diagnosed CG patients includes a wide age range, a range of types of loss and racial and ethnic diversity (white participants comprise 81% of the non-CG and 70% of CG groups). We have a high degree of confidence that those (n=288) who scored at least 30 on the ICG and were diagnosed with CG on clinical interview are suffering from the condition we wish to define.

We conducted a factor analysis focused on these 288 study participants and found a clear 6-factor solution: 1) Yearning and preoccupation with the deceased, 2) shock and disbelief 3) anger and bitterness, 4) estrangement from others, 5) hallucinations of the deceased, and 6) behavior change, including avoidance and proximity seeking. We used the 6 factor groupings in our criteria proposal. We maintain the division of CG symptoms into separation distress (Criterion B) and associated symptoms (Criterion C) because of the Prigerson group's proposal, though a single list of symptoms could also be used. Our factor analysis results guided modifications of B and C criteria. Details of the factor analyses and related sensitivity and specificity analysis are provided in a companion paper. (Submitted to *Depression and Anxiety* by Naomi Simon, et al.)

We found no evidence that yearning is a unique symptom. Rather, it clusters with a group of 4 symptoms in factor 1 (separation distress). These symptoms are listed as Criterion B in our proposed criteria set (Table 2). Another modification is the addition of suicidal thinking and behavior. Given strong evidence reviewed above for an association of CG with suicidality we believe it needs to be included in the diagnostic criteria set. Clinical observation suggests that suicidal thinking and behavior in CG is a manifestation of separation distress and we include it in item B3.

Our factor analysis also guided proposed modifications to the set of symptoms included in Criteria C. Proposed criteria outlined in table 2 group symptoms that clustered together in each of the remaining 5 factors. We also include in this proposal 2 items in Criterion C that were not assessed on the ICG. Item C1 assesses rumination about the circumstances or consequences of the death because there is data for importance of this symptom[85;97;131] and we have observed this symptom frequently in our own work. Item C7 refers to physical and emotional activation on exposure to reminders. This symptom was proposed by Horowitz[16] and has been found to be important in studies by Bonanno and Mancini (personal communication). Again, we have observed this symptom in our clinical work.

We conducted sensitivity and specificity analyses to examine different configurations of symptoms in confirmed compared to non-CG cases. Confirmed CG cases were defined as individuals bereaved at least 6 months who were seeking care for CG, had an ICG > 30, and received a structured clinical interview for CG by a certified clinician confirming CG as their primary illness. Non-cases were bereaved individuals who did not present with CG as a primary complaint (including those with depression, bipolar disorder, anxiety disorders and controls) and had an ICG <25. These analyses showed that yearning alone has a sensitivity of 88.5% so that 11.5% of individuals who we have judged to have CG would be excluded from the Prigerson et al diagnosis. Our Criteria B increases sensitivity to 96.9% and decreases specificity very little. Other results of sensitivity and specificity analyses indicate that requiring symptoms from at least 3 different symptom clusters out of the 6 clusters identified by the factor analysis lead to 95% sensitivity, 98% specificity. Factor 1 is a cluster of separation distress items that correspond to current criterion B in our proposed data. We are proposing to require one of the symptom clusters to be the cluster associated with factor 1. This does not alter the sensitivity and specificity of the criteria compared to having just one grouping of symptoms with a requirement of 3 symptoms endorsed. .

We advocate specifying a timeframe of at least one month of symptoms and impairment (criterion D) and specifying the need for impairment in functioning beyond what is expected in the culture (criterion E). Criterion A specifies that the disorder is not diagnosed until at least 6 months after the death occurs but says nothing about the duration of symptoms. Sometimes grief symptoms surge for a few weeks if a person is under stress or during an anniversary period, and this may not indicate the presence of CG. Therefore, in addition to the time since the loss, we believe a minimum period of one month of CG symptoms should be required.

In summary, building on other criteria proposals,[16;17] other CG research, and new findings from our clinical samples, we propose a modified criteria set that we hope will move the field a step further. We note that development of diagnostic criteria for other diagnoses have typically proceeded in a step wise fashion. The criteria set in DSM-5 is, by definition, at a relatively early stage. Following the procedure previously used successfully and proposed as a model for development of diagnostic criteria in all of clinical medicine[132] entails involvement of groups of credible experts who devise criteria based on existing research findings that are extensive in the case of CG. These criteria can continue to be tested in large epidemiological and clinical samples.

TERMINOLOGY

We favor the term complicated grief (CG). Several authors have suggested that bereavement is analogous to an injury and grief to inflammation associated with the healing process. [133–135] Just as wound healing can be hindered by complications producing a prolonged period of inflammation and soreness, so can healing a loss be hampered by complications producing a prolonged period of acute grief. We believe that the problem with labeling this syndrome “prolonged” or “persistent” grief is that grief is often prolonged or persistent in ways that are not complicated or pathological and this could confuse people. Additionally, the existing literature primarily uses the term complicated (in pubmed: 304 under this keyword v. 48 under prolonged; in psycinfo: 408 v. 24.)

SHOULD COMPLICATED GRIEF SYMPTOMS BE ASSESSED DIMENSIONALLY ACROSS DISORDERS?

Bereavement is a universal experience and grief occurs across all psychiatric diagnoses. It is likely that having a psychiatric diagnosis, especially a mood or anxiety disorder, is a risk factor for the development of complicated grief and that rates of CG are elevated among

psychiatric outpatients.[67] CG has been described in bipolar disorder patients[32] and cardiac bypass patients (Ghesquiere et al in personal communication). Both data sets show evidence of effects of CG on treatment outcome. CG has been identified with a variety of other mental and physical disorders. CG is often under-recognized, under-treated, and is a cause for continuing distress and impairment. There is evidence that CG requires targeted treatment.[111] Additionally, it is possible that grief symptoms could interact with symptoms of other disorders, even when threshold level CG is not present. For these reasons we advocate the use of a simple dimensional measure of CG as a screener to identify CG symptoms. This simple scale was developed for screening people who utilized services after 9–11[37] and has been used in the bypass study (HL7000) as well as several other studies (MH070741, MH060783, MH070547, and MH059395) and a large community sample in Japan[84] all of which documented good psychometric properties. Appendix A provides this measure.

OTHER SUGGESTED REVISIONS FOR DSM IV

DSM IV stipulates that bereaved people should not be diagnosed with major depression unless the symptoms are “unduly severe or prolonged” (p.213), where “severe” is operationalized by a group of 6 symptoms listed under V62.82, and “prolonged” as more than two months after the death. These exclusion criteria are reasonable if the primary goal is to avoid misdiagnosing normal grief. However, Zisook and others have challenged the wisdom of this exclusion.[136–143] Numerous studies from around the world confirm the observation that only about 20% of bereaved people, including children,[144–146] meet criteria for major depression and that depression in the context of bereavement has a course[137–139] and treatment response[107] similar to MDD in other contexts. Findings from at least three studies indicate that depression in the first 2 months after a death responds to medication.[107;147;148] Grief symptoms also improved, though not as much as the depression.

Leaving major depression untreated goes against current clinical guidelines that recommend early identification and treatment. Bereavement may increase the risk of suicide.[149;150] Earlier treatment to reduce suicide risk is likely the most effective long term preventative intervention available[151;152] as risk appears highest in the month before treatment, next highest in the first month after treatment and lower thereafter.[153] Ignoring depression may be more, not less, inhumane and harmful during acute grief.²⁵ DSM IV criteria for adjustment disorder also include a bereavement exclusion. Criterion D states “the symptoms do not represent bereavement,” again likely meant to warn clinicians not to diagnose normal grief. However, there are no guidelines for identifying normal grief. It might be argued that CG is an adjustment disorder, but the bereavement exclusion and lack of criteria for grief maladjustment are important problems.

Finally, Bereavement (V62.82) appears in “Other Conditions That Can Be the Principal Focus of Clinical Attention” (pp 684–685). Acute grief can be highly distressing and disruptive[135;154–157] yet should not be considered an illness.[158] Clinicians might be called upon to support people experiencing acute grief. The bereavement V code can be put to good use if it includes a description of typical acute grief, and more information about when and why the bereavement code should be used. Clinicians could provide reassuring information about grief and support for the mourning process, incorporating awareness of cultural beliefs and mores.

²⁵We note that co-authors Paula Clayton and Michael First are opposed to removing the bereavement exclusion from the diagnosis of major depression

SUMMARY AND CONCLUSION

Bereavement is a universal and severe stressor that regularly evokes a recognizable constellation of painful and debilitating grief symptoms. Most bereaved people are resilient and do not need mental health treatment. However, bereavement does not protect against the development or worsening of mental or physical disorders. On the contrary, as a stressor, bereavement increases risk of illness. Additionally, a subgroup with chronic severe grief has different clinical needs from most bereaved people, and others need treatment for a DSM disorder triggered by the stress of the loss. About 10% of bereaved people develop CG, a condition with a unique constellation of symptoms, unique risk factors and course of illness that requires a specific targeted treatment. We conclude that a new category of complicated grief is needed in DSM-5 and suggest that management of bereaved people can be improved by this and other modifications in DSM-5.

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Appendix A: Brief Dimensional CG Assessment

1. How much are you currently having trouble accepting the death of _____?
 Not at all 0
 Somewhat..... 1
 A lot 2
2. How much does your grief interfere with your life now?
 Not at all 0
 Somewhat 1
 A lot 2
3. How much are you bothered by images or thoughts of _____ when s/he died or other thoughts about the death that really bother you?
 Not at all 0
 Somewhat..... 1
 A lot 2
4. Are there things you used to do when _____ was alive that you don't feel comfortable doing anymore, that you avoid? Like going somewhere you went with him/her, or doing things you used to enjoy together? Or avoiding looking at pictures or talking about _____? How much are you avoiding these things?
 Not at all 0
 Somewhat..... 1
 A lot 2
5. How much are you feeling cut off or distant from other people since _____ died, even people you used to be close to like family or friends?

Not at all	0
Somewhat.....	1
A lot	2

Screen positive: total score ≥ 4

Appendix B: Vignettes of normal and complicated grief

NORMAL GRIEF

Patricia lost her husband Paul to cancer at age 50. They were very close. Twenty years later she still describes his death as the hardest thing she ever went through. She has a vivid memory of the night Paul died. His aggressive cancer had emaciated his body. She sat at his bedside, tears streaming down her face, as he took his last breath. She was surprised at how strange she felt afterward. Even though she had known he was dying, it was hard to comprehend the fact that he was really gone. Patricia had lost her grandmother when she was 30 and they had also been close. She had been sad and missed her grandmother a lot. In fact, she had continued to miss her grandmother all her life. But this was very different. For the first month after Paul died, Patricia could think about little else. She felt intense feelings of yearning and longing for him, and had trouble concentrating on other things. She was grateful that her friends and family brought food and made sure someone was always with her. Their kind words and gentle encouragement weren't really comforting, but it seemed important that they were there. Patricia felt her mind was in a fog and she had little control over her emotions or her thoughts. She knew she wasn't herself. She kept having a strange sensation that Paul would walk through the door. Once, she had awakened in the middle of the night to "see" him standing at the foot of the bed. He seemed to be saying something but she could not understand him. This unnerved her and she talked with her sister who suggested she see a grief counselor. The counselor was very helpful and explained that many people have this kind of experience. She helped Patricia understand that her symptoms were normal. Most people experience intense symptoms when they lose someone so close. After a few months, Patricia noticed that there were hours and then days when the fog lifted. She started to laugh again. She accepted an invitation to go out with friends even though she didn't really want to, and she had a good time. A vision of her life without Paul began to emerge and the intensity of yearning for him subsided. The despair also diminished and she began to feel a different sense of connection to Paul. She continued to miss him a lot over the first few years after he died. There were periods during the second year that seemed even harder than the first, but she got through it and continued to feel increasingly engaged in her current life. Three years after Paul died friends introduced her to Jack, a widower who was very nice. She dated him for about two years. He got along with her children, and she liked his son. They decided to marry. She still thinks about Paul, especially at the anniversary of his death which has remained a difficult time for her. She has learned to take time off from work and to plan some quiet way to honor her relationship with Paul. Jack understands this and is kind and supportive.

COMPLICATED GRIEF

Elaine was a 65 year old woman who lost her husband Steve to cancer 19 years ago. Steve was the love of her life and Elaine was devastated by his death. She had been by his side throughout his illness. She hated thinking that he was going to die, but had thought she was prepared. She expected that she would grieve for a few weeks and the feelings would subside and she would cope. However, the night Steve died, Elaine had been exhausted and had fallen asleep in the hospital day room. She was awakened by a nurse who gently told her that Steve had passed. As it turned out, she was unprepared for the feelings of shock and

disbelief that swept over her as she cried out “NO! NO! NO! Not yet! Not now!” She was caught off guard by the onslaught of symptoms that began immediately and were unremitting. There was a sense of confusion and powerful feelings of protest and despair. She experienced a deep yearning and longing for Steve, and waves of anxiety about how she would manage without him. In the weeks and months that followed, she found respite from painful feelings only by entering a state of foggy numbness that felt like a veil separating her from the rest of the world, or by daydreaming about her life with Steve. She felt strangely disconnected from her friends and even from her children. It was hard to think about anything other than Steve, as she reviewed in her mind his many talents and admirable traits and the unfairness of his illness and death. She could not remember ever feeling so helpless. It seemed that she didn’t know what to say to other people and felt barely capable of shopping in a grocery store or completing the simplest chore. She soon began trying to avoid reminders that would trigger intense emotions or physical symptoms. She ruminated on the tragedy of Steve’s premature death and puzzled over why others did not seem devastated by the loss of this wonderful man. Her life had never felt so out of control.

Elaine was the only child of parents who were rigid and cold. She knew they loved her but felt she could never please them and she couldn’t trust them to understand or soothe her. They fought with each other and were harsh and demanding of her. She said she had raised herself and had not considered herself an appealing person. As an adolescent she had felt awkward and unattractive, especially on dates. She had a boyfriend in college but they broke up after graduation. After that, she focused on her work where, unlike dating, she felt socially at ease. She worked as a special events planner, a job that suited her meticulous personality and general enjoyment of social activities. Clients and coworkers admired her and she loved her work. She met Steve when she was in her early 30’s. He was an educator, with a reserved demeanor and an intellectual approach to life. Steve worked as the Head of small elite secondary school, where he was beloved as an administrator and admired as a scholar. Elaine was drawn to his kindness and quiet contemplative nature and impressed by the breadth and depth of his knowledge. Steve was attracted to Elaine’s combination of shyness and warmth. He admired her organizational skills and her quick wit. They learned they had a lot of shared values and life goals. They recognized each other as soul mates and were married within 6 months of meeting. Elaine never expected to find someone like Steve, and she loved him with all her heart. They had 2 children and an active family life. They were very happy until shortly after their 25th wedding anniversary when he developed a virulent cancer. She was devastated and took a leave of absence from her job to be with Steve as much as possible. During what turned out to be a 7 month illness she watched him “disappear before my eyes.” After he died she was plagued by the thought that she should have done more. She never forgave herself for falling asleep in another room on the night that he died. She should have been with him. She should have made sure he never got cancer. She should have done more to help him when he was ill. She couldn’t live without him.

Elaine decided she had not realized that she was so dependent on Steve and began to think their relationship was “not healthy.” She frequently thought it would have been better for her to have died instead of him. She often considered suicide but was stopped by the thought that she might not ever be reunited with her beloved husband. Caught up in thoughts of Steve as an extraordinary person and herself as pathetic and weak, she began to feel hopeless and depressed. Her intense grief continued unremitting. Eventually, her friends and family lost patience with her. Her closest friend told her that she needed to stop wallowing in her grief and move on. If Elaine couldn’t do this, she should get help. Elaine consulted Dr. M, a psychiatrist, and found him kind and supportive. He told her she was depressed and prescribed medication that was somewhat helpful. He sent her to a grief counselor whom she saw for about a year. Elaine liked the counselor, but her symptoms did not remit and

eventually she stopped going. Dr. M tried to talk with her about her idealization of her husband and suggested that she must be angry at Steve for leaving her. These efforts fell on deaf ears, and there was little change over the years. Elaine's life consisted of weekly visits to Dr. M, the only place she could talk about Steve and feel some comfort. She changed jobs and did only what was needed to make ends meet. In the evenings she stayed home. When she tried to venture elsewhere, she was assaulted by reminders Steve's loss. "I was convinced that all I needed was to have Steve back and Dr. M couldn't do that." she said when she presented for treatment of complicated grief, "but at least he let me talk about Steve. He was my lifeline." Elaine found information on a website that described complicated grief and thought, maybe someone finally understood. She said, "I saw immediately that this was my problem."

Table 1

Normal and Complicated Grief

COMMON SYMPTOMS OF ACUTE GRIEF THAT ARE WITHIN NORMAL LIMITS WITHIN THE FIRST 6–12 MONTHS AFTER
<ul style="list-style-type: none"> • Recurrent, strong feelings of yearning, wanting very much to be reunited with the person who died; possibly even a wish to die in order to be with deceased loved one • Pangs of deep sadness or remorse, episodes of crying or sobbing, typically interspersed with periods of respite and even positive emotions • Steady stream of thoughts or images of deceased, may be vivid or even entail hallucinatory experiences of seeing or hearing deceased person • Struggle to accept the reality of the death, wishing to protest against it; there may be some feelings of bitterness or anger about the death • Somatic distress, e.g. uncontrollable sighing, digestive symptoms, loss of appetite, dry mouth, feelings of hollowness, sleep disturbance, fatigue, exhaustion or weakness, restlessness, aimless activity, difficulty initiating or maintaining organized activities, altered sensorium <p>Feeling disconnected from the world or other people, indifferent, not interested or irritable with others</p>
SYMPTOMS OF INTEGRATED GRIEF THAT ARE WITHIN NORMAL LIMITS
<ul style="list-style-type: none"> • Sense of having adjusted to the loss • Interest and sense of purpose, ability to function, and capacity for joy and satisfaction are restored, • Feelings of emotional loneliness may persist • Feelings of sadness and longing tend to be in the background but still present • Thoughts and memories of the deceased person accessible and bittersweet but no longer dominate the mind • Occasional hallucinatory experiences of the deceased may occur <p>Surges of grief in response to calendar days or other periodic reminders of the loss may occur</p>
COMPLICATED GRIEF
<ul style="list-style-type: none"> • Persistent intense symptoms of acute grief <p>The presence of thoughts, feelings or behaviors reflecting excessive or distracting concerns about the circumstances or consequences of the death</p>

Table 2

Proposed criteria for Complicated Grief

A. The person has been bereaved, i.e. experienced the death of a loved one, for at least 6 months	
B. At least one of the following symptoms of persistent intense acute grief has been present for a period longer than is expected by others in the person's social or cultural environment	
1	Persistent intense yearning or longing for the person who died
2	Frequent intense feelings of loneliness or like life is empty or meaningless without the person who died
3	Recurrent thoughts that it is unfair, meaningless or unbearable to have to live when a loved one has died, or a recurrent urge to die in order to find or to join the deceased
4	Frequent preoccupying thoughts about the person who died, e.g. thoughts or images of the person intrude on usual activities or interfere with functioning
C. At least 2 of the following symptoms are present for at least a month:	
1	Frequent troubling rumination about circumstances or consequences of the death, e.g. concerns about how or why the person died, or about not being able to manage without their loved one, thoughts of having let the deceased person down, etc.
2	Recurrent feeling of disbelief or inability to accept the death, like the person can't believe or accept that their loved one is really gone
3	Persistent feeling of being shocked, stunned, dazed or emotionally numb since the death
4	Recurrent feelings of anger or bitterness related to the death
5	Persistent difficulty trusting or caring about other people or feeling intensely envious of others who haven't experienced a similar loss
6	Frequently experiencing pain or other symptoms that the deceased person had, or hearing the voice or seeing the deceased person
7	Experiencing intense emotional or physiological reactivity to memories of the person who died or to reminders of the loss
8	Change in behavior due to excessive avoidance or the opposite, excessive proximity seeking, e.g. refraining from going places, doing things, or having contact with things that are reminders of the loss, or feeling drawn to reminders of the person, such as wanting to see, touch, hear or smell things to feel close to the person who died. (Note: sometimes people experience both of these seemingly contradictory symptoms.)
D. The duration of symptoms and impairment is at least 1 month	
E. The symptoms cause clinically significant distress or impairment in social, occupational or other important areas of functioning, where impairment is not better explained as a culturally appropriate response	

TABLE 3

Prigerson et.al. 2009	Shear et.al. 2010	Comments
A. Bereavement (loss of a significant other)	A. The person has been bereaved, i.e. experienced the death of a loved one, for at least 6 months	
B. Separation Distress: The bereaved person experiences yearning (e.g. craving, pining, or longing for the deceased; physical or emotional suffering as a result of the desired but unfulfilled reunion with the deceased) daily or to a disabling degree	B. At least one of the following symptoms of persistent intense acute grief has been present for a period longer than is expected by others in the person's social or cultural environment 1. Persistent intense yearning or longing for the person who died 2. Frequent intense feelings of loneliness or like life is empty or meaningless without the person who died	Separation distress can be manifest in several different ways. A meaningful minority of people who meet criteria for CG by other methods do not endorse yearning.
C. Cognitive, emotional and behavioral symptoms: The bereaved person must have five or more of the following symptoms experienced daily or to a disabling degree:	3. Recurrent thoughts that it is unfair, meaningless or unbearable to have to live when a loved one has died, or a recurrent urge to die in order to find or to join the deceased 4. Frequent preoccupying thoughts about the person who died, e.g. thoughts or images of the person intrude on usual activities or interfere with functioning	Suicidal thinking and behaviors are elevated in CG and are important symptoms
1. Confusion about one's role in life or diminished sense of self (i.e. feeling that a part of oneself has died)	C. At least 2 of the following symptoms are present for at least a month:	It is important that these symptoms are all related to the death.
2. Difficulty accepting the loss	1. Frequent troubling rumination about circumstances or consequences of the death, e.g. concerns about how or why the person died, or about not being able to manage without their loved one, thoughts of having let the deceased person down, etc. 2. Recurrent feeling of disbelief or inability to accept the death, like the person can't believe or accept that their loved one is really gone	Rumination is a clinically significant symptom of CG
3. Avoidance of reminders of the reality of the loss	3. Persistent feeling of being shocked, stunned, dazed or emotionally numb since the death	
4. Inability to trust others since the loss	4. Recurrent feelings of anger or bitterness related to the death	People with CG are mistrustful because they feel that others don't understand them or are critical of them
5. Bitterness or anger related to the loss	5. Persistent difficulty trusting or caring about other people or feeling intensely envious of others who haven't experienced a similar loss	
6. Difficulty moving on with life (e.g. making new friends, pursuing new interests)	6. Frequently experiencing pain or other symptoms that the deceased person had, or hearing the voice or seeing the deceased person	
7. Numbness (absence of emotion) since the loss	7. Experiencing intense emotional or physiological reactivity to memories of the person who died or to reminders of the loss	
8. Feeling that life is unfulfilling, empty or meaning/less since the loss	8. Change in behavior due to excessive avoidance or the opposite, excessive proximity seeking, e.g. refraining from going places, doing things, or having contact with things that are reminders of the loss, or feeling drawn to reminders of the person, such as wanting to see, touch, hear or smell things to feel close to the person who died. (Note: sometimes people experience both of these seemingly contradictory symptoms.)	

Prigerson et.al. 2009	Shear et.al. 2010	Comments
<p>9. Feeling stunned, dazed or shocked by the loss</p>	<p>9. Disturbing emotional or physiological reactivity to reminders of the loss</p>	<p>This item is strongly related to CG symptoms in Bonanno studies and is clinically meaningful</p>
<p>D. Timing: Diagnosis should not be made until at least six months have elapsed since the death</p>	<p>D. The duration of symptoms and impairment is at least 1 month</p>	<p>Need minimum duration of symptoms. CG is not diagnosed until at least 6 months after the loss but some people have transient increases in symptoms after that time and should not be considered to have CG</p>
<p>E. Impairment: The disturbance causes clinically significant impairment in social, occupational or other important areas of functioning (e.g. domestic responsibilities)</p>	<p>E. The symptoms cause clinically significant distress or impairment in social, occupational or other important areas of functioning, where impairment is not better explained as a culturally appropriate response</p>	<p>we added distress, in line with other DSM diagnoses, and the possibility that impairment might be explained as a culturally appropriate response -e.g. when certain activities are not considered appropriate until a year has passed</p>
<p>F. Relation to other mental disorders: The disorder is not better accounted for by major depressive disorder , generalized anxiety disorder or posttraumatic stress disorder</p>		<p>We favor omission of this criterion in line with thinking of other work groups about the difficulties of hierarchical diagnoses</p>