



# An overview of complicated grief terminology and diagnostic criteria

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## Abstract

This article sets the scene for the current debate on the concept of complicated grief. Issues identified with diagnosis of individuals with complicated grief include concerns about misuse of the term, distinctions between normal and complicated grief and fears regarding stigmatisation associated with potential DSM-V classification of complicated grief. Use of the term as described by Prigerson and colleagues reflects current best evidence, addresses concerns related to definitional error and would assist in progressing research and clinical practice in a more consistent manner if this were used by clinicians, researchers, health policy makers and educators. Such progress will be further assisted when consensus on the diagnostic criteria for complicated grief is achieved.

The nature of complicated grief and its relationship to other syndromes and conditions and questions about how complicated grief should be defined, assessed, and classified, have been topics of significant and persistent debate (Stroebe, van Son, Stroebe, Kleber, Schut, et al., 2000). Researchers have hypothesised that a small, though significant percentage of the population (approximately 10% - 20%) experience complicated grief, and that these individuals are at greatest risk for adverse health effects (Byrne & Raphael, 1994; Middleton, Burnett, Raphael, & Martinek, 1996; Prigerson & Jacobs, 2001a). However, there has been a lack of evidence for good practice in bereavement research and services, especially for those who might be 'at risk' of complicated grief following bereavement. In addition, there has been great diversity in the adjectives used to describe variations from normal grief and the conceptualisations of complicated grief differed according to the theoretical approach taken by the investigators. This definitional and theoretical confusion has created uncertainty for health care providers and services that endeavour to make sense of the complex and apparently conflicting literature.

## Normal grief

Shear and Shair (2005), in a recent review, give a succinct outline of the difference between normal grief and complicated grief. They describe normal grief as the state that occurs when people "are deeply saddened by the death of an attachment figure during a period of weeks or months of acute grief" (p. 253). They acknowledge the individuality of grief and that responses vary. However, the person who typifies normal grief experiences "an intense yearning, intrusive thoughts and images, and/or a range of dysphoric emotions" (p. 253) and that these symptoms do not persist. The initial reaction subsides, interest and engagement in daily activities is renewed and the loss

is integrated into the bereaved person's on-going life. As this integration occurs "painful feelings lessen and thoughts of the loved one cease to dominate the mind of the bereaved" (p. 253).

For a minority of people, a normal grief adjustment does not occur. It is estimated that between 10% and 20% of people find coping painful and difficult (Byrne & Raphael, 1994; Middleton et al., 1996; Prigerson & Jacobs, 2001a). Shear and Shair (2005) propose that for this small percentage of people, "integration of the loss does not occur and acute grief is prolonged in the form of complicated grief". People who suffer from complicated grief experience a sense of "persistent and disturbing disbelief regarding the death". There are feelings of "anger, bitterness, and resistance to accepting the painful reality". Intense yearning and longing for the deceased continue, along with frequent pangs of intense, painful emotions "Thoughts of the loved one remain preoccupying often including distressing intrusive thoughts related to the death, and there is avoidance of a range of situations and activities that serve as a reminder of the painful loss. Interest and engagement in ongoing life is limited or absent" (p. 253).

## Complicated grief

A recent systematic literature review on complicated grief indicates that the majority of key researchers in the field agree that complications of grief do exist (Kristjanson, Lobb, Aoun, & Monterosso, 2006). However, the terminology, definitions and criteria used to describe complicated grief have not been consistent (Neimeyer, 2006; Prigerson, & Maciejewski, 2006; Walter, 2006).

The diagnostic term for "complications that arise from grief" has been variably defined over the past 20 years, with a multitude of adjectives used to describe variations from normal grief. These adjectives include absent, abnormal, complicated, distorted, morbid, maladaptive, atypical, intensified and prolonged, unresolved, neurotic, dysfunctional, chronic, delayed, and inhibited. Further refinement of this terminology has occurred and more consistency appeared in the literature around 1983 with the use of terminology such as delayed or absent grief, inhibited or distorted grief and chronic grief (Parke & Weiss, 1983; Raphael, 1983).

Historically, researchers have argued that complicated grief is an expression of a major depressive disorder or an anxiety-based disorder, that has been triggered by the death (Brent, Perper, Moritz, Allman, Schweers, et al., 1993; Kim, & Jacobs, 1991). More recently, researchers have concluded that grief symptoms only partially overlap with symptoms of depression and other DSM categories such as anxiety and post traumatic stress disorder and that although there

may be some expected shared variance, complicated grief reactions do display sufficient unique variance to warrant separate consideration (Horowitz, Siegel, Hoken, Bonanno, Milbrath, et al., 1997; Kim & Jacobs, 1991; Marwit, 1991, 1996; Prigerson, Bierhals, Kasl et al., 1996; Prigerson et al., 1995).

Within the last decade several studies have attempted to establish a definition of complicated grief that extends beyond clinical descriptions and that allows for empirical validation (Horowitz et al., 1997; Prigerson & Jacobs, 2001b; Prigerson, Maciejewski, Reynolds, Bierhals, Newsom et al., 1995; Raphael, 1983; Raphael & Martinek, 1997). Most current researchers have attempted to identify the symptoms of complicated grief by the taxonomy provided by Prigerson and Jacobs (2001b) that follows the format of existing disorders in the DSM. Their rationale is that if the requirements for a distinct psychiatric illness are met, then complicated grief should be considered as a separate diagnosis.

Prigerson and Jacobs (2001b) suggested that symptoms of complicated grief fall into two categories: (a) symptoms of separation distress, such as longing and searching for the deceased, loneliness, preoccupation with thoughts of the deceased and (b) symptoms of traumatic distress, such as feelings of disbelief, mistrust, anger, shock, detachment from others, and experiencing somatic symptoms of the deceased. This schema allowed bereavement experts to identify a class of symptoms for a disorder of grief and the Inventory of Complicated Grief-Revised has been developed to measure these sets of symptoms (Prigerson & Jacobs, 2001b).

These symptoms are proposed by Maciejewski (2005) to be indicative of pathology and that "the issue is not whether the symptoms sort themselves into seemingly pathological versus seemingly normal symptom clusters" (p. 15), but that the set of complicated grief symptoms identified is persistent (beyond six months post-death) regardless of when those six months occur in relation to the loss, and severe (marked intensity or frequency, such as several times daily) and predict many negative outcomes distinguishing them from normal grief symptoms.

Prigerson previously used the term "Traumatic Grief" because it was felt that the term captured the essence of the underlying forms of symptomatic distress, conceptualised in the original version of the Inventory of Complicated Grief developed in 1995. After the 9/11 terrorist attacks in the United States of America, the need to distinguish a grief disorder from Post Traumatic Stress Disorder became apparent (Prigerson, Vanderwerker, & Maciejewski, in press). As a result, Prigerson and colleagues reverted to their original term of "Complicated grief" in an attempt to minimise confusion between this reaction to loss and the psychological reaction following exposure to traumatic events such as the 9/11 attacks (i.e. Post-traumatic Stress Disorder). Prigerson perceived a basic distinction between Complicated grief, which was rooted in interpersonal attachment issues, and Post Traumatic Stress Disorder, which was grounded in a sense of impending dangerous events feared likely to harm one-self or others. The decision to revert back to

the term "Complicated grief" was made to clarify the distinction between these two disorders.

Differences of opinion about complicated grief in the literature appear to focus on the lack of agreement among scientists on the specifics of the diagnostic criteria and their categorisation, determination of the boundaries between normality and pathology, concerns about social coercion and issues of stigmatisation (Stroebe & Schut, 2006).

#### Diagnostic criteria for complicated grief

In recent years, studies have been undertaken to provide the empirical data that would establish complicated grief as a distinct clinical entity. Thus complicated grief would be a unified syndrome distinct from bereavement-related depression and anxiety and from normal reactions to bereavement. The debate in these studies centres around the extent to which complicated grief represents a truly unique pathological entity, when contrasted with depressive or anxiety disorder, post-traumatic stress disorder (PTSD), and "uncomplicated grief" (Goodkin, Lee, Molina, Zheng, Frasca, et al., 2006).

Key researchers active in debating and establishing diagnostic criteria for complicated grief include Mardi Horowitz and his colleagues at the University of California and Holly Prigerson and her colleagues at Yale University. Each of these groups has proposed a different set of diagnostic criteria.

#### Horowitz' criteria

In establishing their criteria, Horowitz and colleagues (Horowitz et al., 1997) followed the method of the Structured Clinical Interview used for DSM-III-R along with self-report rating scales in subjects studied 6 and 14 months after bereavement. They identified 30 questions relating to possible symptoms of complicated grief. The data were analysed using sophisticated methods of 'latent class' and 'signal detection' techniques in order to produce a model set of criteria for complicated grief complicated grief disorder. The criteria are shown in Table 1. In a sample of 70 self-selected bereaved subjects, 41% met these criteria for complicated grief 14 months after the loss. Thirty-one percent met criteria for Major Depressive Disorder (MDD) with a concordance of both diagnoses in only 9%. Despite this relatively low concordance, a previous history of depression or anxiety disorder was associated with a significantly increased risk of complicated grief

Table 1  
Criteria for Complicated Grief Disorder (Horowitz et al., 1997)

<b>A. Event Criterion/ Prolonged Response Criterion</b>
Bereavement (Loss of spouse, other relative or intimate partner) at least 14 months ago (to avoid anniversary)
<b>B. Signs and Symptoms Criteria</b>
In the last month any three of the following, with a severity that interferes with daily functioning:
Intrusive Symptoms
1. Unbidden memories or intrusive fantasies related to the lost relationship.
2. Strong spells or pangs of severe emotion related to the lost relationship.
3. Distressing strong yearnings or wishes that the deceased were there.
Signs of Avoidance and Failure to Adapt
4. Feeling of being far too much alone or personally empty
5. Excessively staying away from people, places or activities that remind the subject of the deceased
6. Unusual levels of sleep interference.
7. Loss of interest in work, social, care taking, or recreational activities to a maladaptive degree

**Prigerson's criteria**

Prigerson's group first developed their 'Inventory of Complicated Grief' in 1995 (Prigerson, Maciejewski et al., 1995) and have subsequently demonstrated its specificity, reliability, validity and ability to predict a variety of measures of physical and mental health in a series of studies (Prigerson, Bierhals, Kasl et al., 1996; Prigerson, Bierhals, & Zonarich, 1996; Prigerson, Frank, Kasl, Reynolds, Anderson et al., 1995; Prigerson, Maciejewski et al., 1995). This has been the tool on which consensus criteria were developed in 2001 (Prigerson & Jacobs, 2001b).

In this paper the authors describe the process through which the criteria were established (Prigerson & Jacobs, 2001b). Initially, a consensus conference was convened to review the evidence and develop a preliminary set of criteria. The group agreed that, for the time being,

bereavement by death should be an essential criterion as should symptoms of separation distress which they see as at the core of the diagnosis. Because these criteria do not distinguish complicated from uncomplicated grief, they added three further requirements: symptoms of traumatisation, impairment of functioning and, that the condition has continued for at least six months from the time of onset (which, in the case of delayed reactions, is not from the time of death).

Prigerson and colleagues proceeded to test the consensus criteria in a non-treatment seeking community-based sample of bereaved and the latest criteria and assessment are the result of that research (Prigerson, Jacobs, Horowitz, Parkes, Raphael, et al., submitted for publication; H. G. Prigerson, personal communication, 2006). This full set of new criteria is reproduced with permission in Table 2.

Table 2  
Prigerson's Criteria for Complicated grief Proposed for DSM-V \*

<b>Criterion A:</b> Chronic and persistent yearning, pining, longing for the deceased, reflecting a need for connection with deceased that cannot be satisfied by others. Daily, intrusive distressing and disruptive heartache.
1. <b>Yearning/longing/heartache</b> - 'Do you feel yourself yearning and longing for the person who is gone?'
<b>Criterion B:</b> The person should have four of the following eight remaining symptoms at least several times a day or to a degree intense enough to be distressing and disruptive:
1. <b>Trouble accepting the death</b> - 'Do you have trouble accepting the loss of ___?'
2. <b>Inability to trust others</b> - 'To what extent has it been hard for you to trust others since the loss of ___?'
3. <b>Excessive bitterness or anger related to the death</b> - 'Do you feel angry about the loss of ___?'
4. <b>Uneasy about moving on</b> - 'Sometimes people who lose a loved one feel uneasy about moving on with their life. To what extent do you feel that moving on (for example, making new friends, pursuing new interests) would be difficult for you?'
5. <b>Numbness/Detachment</b> - 'Do you feel emotionally numb or have trouble feeling connected with others since ___ died?'
6. <b>Feeling life is empty or meaningless without deceased</b> - 'To what extent do you feel that life is empty or meaningless without ___?'
7. <b>Bleak future</b> - 'Do you feel that the future holds no meaning or prospect for fulfilment without ___?'
8. <b>Agitated</b> - 'Do you feel on edge or jumpy since ___ died?'
<b>Criterion C:</b> The above symptom disturbance causes marked and persistent dysfunction in social, occupational, or other important domains.
<b>Criterion D:</b> The above symptom disturbance must last at least six months.
<b>Complicated grief diagnosis</b> = Criteria A, B, C and D must be met.

*Note.* From Prigerson, H. G., & Maciejewski, P. K. (2006). A call for sound empirical testing and evaluation of criteria for complicated grief proposed for DSM-V. *Omega: The Journal of Death & Dying*, 52, 1-7. -Reproduced with the permission of the author.

There is agreement that "based upon the research to date, the criteria set proposed by Prigerson et al. appears to have advantages over that proposed by Horowitz et al. (1997) as evidenced by higher estimation of internal consistency and in construct validity (related to its focus upon separation distress and impaired social and occupational function)" (Goodkin et al., 2006, p. 32).

Parkes (2006a) agrees that Prigerson's criteria best meet the psycho-metric requirements, and that Horowitz' criteria fails to clearly differentiate complicated grief from other possible consequences of bereavement and that their criteria places undue emphasis on traumatic avoidance.

#### The inclusion of diagnostic criteria for complicated grief in DSM V

The DSM is a non-theoretical categorisation system with an emphasis on phenomenology, etiology, and course as defining features of mental disorders. It offers guidance to mental health professionals with regard to what is pathological and what is normal (Lichtenthal, Cruess, & Prigerson, 2004). The existing DSM-IV-TR has recognised that grief symptoms may warrant clinical attention; however, they do not acknowledge complicated grief's unique set of symptoms (Lichtenthal et al., 2004). The DSM classifies bereavement as a normal stressor, but more severe pathology is classified in existing diagnostic categories (e.g., Major Depressive Disorder) (Bonanno & Kaltman, 2001).

Prigerson and colleagues call for complicated grief to be established as a unique diagnosis. However, Stroebe et al. (2000) caution that the inclusion of complicated grief in DSM would have far reaching impact as it is "a leading guide for practitioners" (p. 58) and there is a need to look at appropriate care for the bereaved. Some people would benefit from receiving treatment, but may not be able to obtain access to it because complicated grief does not have a diagnosis category. However, "there is a need to ensure that appropriate guidelines are developed so that therapy is appropriate" (pp. 58-59).

Other concerns are that DSM IV-TR is culturally bound and that the diagnosis category of bereavement needs to be expanded to deal with Indigenous people's experience of "broad-based cultural losses" (Walle, 2004, p. 52). One argument is that the relatively small subset of people who experience complicated grief are adequately captured by existing diagnosis categories in the DSM as they "[appear] to experience symptoms similar to individuals suffering from depression and anxiety disorders, and to some extent trauma reactions" (Bonanno & Kaltman, 2001, p. 710). Horowitz suggests that complicated grief disorder (preferred term) should be included in a separate category of Stress Response Syndromes or in a separate category of its own with diagnostic criteria (Horowitz, 2006). Goodkin et al. (2006) suggest a compromise position that incorporates complicated grief into DSM-V, but relegates it to Appendix B (disorders proposed for further study) due to the lack of clarity surrounding its diagnostic criteria. Prigerson & Maciejewski (2006) agree with Goodkin, et al. (2006) and Stroebe and Shut (2006) when they note that the Horowitz criteria (Horowitz et al., 1997) places undue emphasis on traumatic avoidance. Prigerson and Vanderwerker (2006) recommend that

the focus of the criteria for complicated grief "is on the relationship and the meaning behind (and in front) of the loss of the important relationship the survivor has lost" (p. 92). Therefore, they recommend that complicated grief "neither be grouped among mood nor anxiety disorders (including PTSD and similar stress response syndromes), not be event based, but rather be placed separately within a new category of Attachment Disorders" (p. 92).

Stroebe and Schut (2006) summarise the current different views of researchers active in debating and establishing a diagnostic categorisation of complicated grief in the DSM V:

1. Complicated grief should be incorporated within the DSM classification system's diagnostic category PTSD.
2. Two separate categories are needed, PTSD (for traumatic bereavement) and complicated grief (for non-traumatic bereavement)
3. A new category of "traumatic grief" (specifically for disordered grieving following a traumatic bereavement) should be developed.
4. A new category of complicated grief covering non-traumatic and traumatic bereavement experiences is called for.
5. Complicated grief is an entity separate from trauma, following non-traumatic bereavement; complicated grief alone should be the focus and concern in developing a new category.

Parkes (2006b) supports Prigerson and Horowitz in position 5 and expresses the view that "the concept of complicated grief is now so well supported that it deserves to be recognised as a specific disorder" (p. 110) rather than be assigned to any of the suggested related categories.

Following the recent publication of a special edition of *Omega: The Journal of Death & Dying* on complicated grief, the main issue of contention continues to be a lack of consensus on the specific criteria proposed for complicated grief.

As evidence of the wish to compromise and to achieve consensus, Prigerson and Horowitz are drafting a compromise criteria set and upon finalising it, will distribute it to clinicians and researchers for further clarification, revision, and arbitration until consensus is achieved (H. Prigerson, personal communication, May, 2006).

#### Conclusion

There is evidence to confirm that complicated grief does occur in small proportions within the bereaved population. Future discussions will determine if complicated grief should be included in the DSM-V. Issues identified with diagnosis of individuals with complicated grief include concerns about misuse of the term, distinctions between normal and complicated grief, fears regarding stigmatisation and health insurance funding issues associated with potential DSM-V classification of complicated grief. Use of the term as described by Prigerson and colleagues reflects current best evidence, addresses concerns related to definitional error and will assist in progressing research and clinical practice in a more consistent manner if this were used by clinicians, researchers, health policy makers and educators.

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