The importance of harmonising diagnostic criteria sets for pathological grief

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Summary

Five different diagnostic criteria sets for pathological grief are currently used in research. Studies evaluating the performance of these sets indicate that it is not justified to generalise findings regarding prevalence rates and predictive validity across studies using different diagnostic criteria of pathological grief. We provide recommendations to move the bereavement field forward.
Yearning for a significant other who has died, being preoccupied with the loss and circumstances surrounding it, and sadness are reactions frequently experienced by bereaved people. Most people adapt to the death of a significant other over time (1). When grief reactions interfere with daily life tasks for a prolonged period of time following the death, a diagnosis of a grief disorder (i.e., pathological grief) might apply. Factor analytic studies and latent class analyses have shown that pathological grief reactions are related to, yet distinguishable from, symptoms of depression and posttraumatic stress disorder (PTSD) (2, 3). In addition, it has been shown that people with pathological grief benefit from grief-focused treatment more than from non-grief-focused treatment (4, 5). A meta-analysis has shown that one out of ten bereaved people are at risk for experiencing pathological grief after a natural death (e.g., due to illness) (6). Caution is, however, warranted when interpreting the findings of this meta-analysis, because of several limitations. The included studies varied in terms of study sample (e.g., representative vs. non-representative samples), operationalisation of pathological grief (i.e., different diagnostic criteria sets for pathological grief were used), and measurement of pathological grief (i.e., different surveys and few clinical diagnostic interviews were used).

Efforts by clinical and research experts have led to the inclusion of grief disorders in recent editions of the two most frequently used diagnostic classification systems in mental health care; the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (7) and the International Classification of Diseases (ICD-11) (8). Earlier, Prigerson et al. (9) proposed a set of criteria for Prolonged Grief Disorder (PGD; hereafter referred to as PGD-2009) and Shear et al. (10) proposed a different set for Complicated Grief (CG). Psychometric properties of the latter two criteria sets have been evaluated with methods from classical test theory and item response theory (9, 11). Independently, both research groups concluded that the criteria
sets they proposed for pathological grief adequately differentiate bereaved people with non-pathological grief from those with pathological grief.

The 10 criteria for PGD-2009 and 13 criteria for CG were eventually not included in the DSM-5 and ICD-11. Instead, a combination of these two sets, named Persistent Complex Bereavement Disorder (PCBD), was included as one of the ‘other specified trauma- and stressor-related disorders’ and as a condition for further study in Section III of DSM-5 (7). Due to the preliminary nature of criteria sets in Section III, it can be expected that the operationalisation and/or naming of PCBD will change in future revisions of the DSM. PCBD can be diagnosed when, following the death of a significant other, at least one of four separation distress symptoms and at least six of 12 symptoms of reactive distress and social/identity disruption are present to the point of impairment at least 12 months (6 months for children) after the death (7). In addition, PGD was recently included in the ICD-11 (8). PGD can be diagnosed 6 months post-loss, when at least one out of two separation distress symptoms combined with at least one out of 10 accompanying symptoms are present to the point of impairment (8, 12, 13).

PCBD as per DSM-5 seems to be a compromise between the two proposed diagnostic criteria sets by Prigerson et al. (9) and Shear et al. (10), augmented with three additional criteria (14). In a beta-draft of the ICD-11 (15), a version of PGD was introduced encompassing 7 criteria (hereafter referred to as beta-draft ICD-11 PGD). The final version of PGD as per ICD-11 (8) (hereafter referred to as ICD-11 PGD) encompasses 12 diagnostic criteria. Beta draft ICD-11 PGD and ICD-11 PGD seem to be based on Prigerson et al.’s (9) PGD proposal, but with some alterations (12). Thus, over the past decade, five different criteria sets have been proposed in the literature. Figure 1 provides an overview of the similarities and differences between these five diagnostic criteria sets (see also Table 1 in Supplementary Material).
Figure 1. Similarities and differences between five diagnostic criteria sets of pathological grief

**Brief symptom description**
1. Persistent yearning/longing for the deceased.
2. Intense sorrow and emotional pain.
3. Preoccupation with the deceased.
4. Preoccupation with the circumstances of the death.
5. Marked difficulty accepting the death.
6. Experiencing disbelief/emotional numbness over the loss.
7. Difficulty with positive reminiscing about the deceased.
8. Bitterness or anger related to the loss.
9. Maladaptive appraisals about oneself (e.g., self-blame).
10. Excessive avoidance of reminders of the loss.
11. A desire to die in order to be with the deceased.
12. Difficulty trusting other individuals since the death.
13. Feeling alone or detached from others.
14. Feeling that life is meaningless or empty without deceased.
15. Confusion about one’s role in life (e.g., feeling that a part of oneself died).
16. Difficulty to pursue interests or to plan for the future.
17. Guilt.
18. Denial.
20. An inability to experience positive mood.
21. Feeling stunned, dazed or shocked by the loss.
22. Feeling envious of others who have not experienced a loss.
23. Frequently experiencing pain or other symptoms that the deceased person had, or hearing the voice or seeing the deceased person.
24. Experiencing intense emotional or physiological reactivity to memories of the person who died or to reminders of the loss.
25. Change in behavior due to excessive proximity seeking (e.g., doing things that are reminders of the loss).
Note. CG = Complicated Grief; PCBD = Persistent Complex Bereavement Disorder; PGD = Prolonged Grief Disorder. For illustrative purposes, the following compound CG criteria are displayed as two symptoms rather than one symptom: criterion B2 ‘Frequent intense feeling of loneliness or like life is empty or meaningless without the person who died’ displayed as symptom 13 and 14, criterion C2 ‘Recurrent feeling of disbelief or inability to accept the death, like the person cannot believe or accept that their loved one is really gone’ displayed as symptom 5 and 6, criterion C3 ‘Persistent feeling of being shocked, stunned, dazed, or emotionally numb since the death’ displayed as symptom 6 and 21, criterion C5 ‘Persistent difficulty trusting or caring about other people or feeling intensely envious of others who have not experienced a similar loss’ displayed as symptom 12 and 22, and criterion C8 ‘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’ displayed as symptom 10 and 25.
Research has shown that different prevalence rates for pathological grief are found when applying different criteria sets. In addition, evidence in support of predictive validity for some criteria sets (i.e., CG and ICD-11 PGD) is lacking. Maciejewski et al. (16) showed that interview-based DSM-5 PCBD, PGD-2009, and beta-draft ICD-11 PGD in a community bereaved sample are similar in terms of prevalence rates (~ 10%) and predictive validity (i.e., presence of diagnosis significantly predicted more functional impairment and lower quality of life over time), whereas CG showed higher prevalence rates (30%) and lacked predictive validity (i.e., presence of a CG diagnosis did not predict functional impairment or decreased quality of life over time).

Cozza et al. (17) and Mauro et al. (18) examined whether different diagnostic criteria sets of pathological grief (survey-based or interview-based) resulted in differences regarding detecting clinical cases in a sample of bereaved families of military personnel and in a treatment-seeking sample, respectively. A predefined criterion for ‘caseness’ was used; scores of 30 or higher on the Inventory of Complicated Grief were considered an indication of ‘caseness’ and scores below 20 indicated ‘non-caseness’. People whose Inventory of Complicated Grief score fell between 20 and 30 were not included in the studies. Both Cozza et al. (17) and Mauro et al. (18) concluded that CG criteria were superior when it comes to correctly identifying clinical cases (i.e., over 90% of clinical cases were detected), while DSM-5 PCBD and PGD-2009 criteria were too stringent (i.e., 50-70% of clinical cases were detected). Mauro et al. (13) compared the diagnostic criteria of interview-based PGD-2009 with ICD-11 PGD in a treatment-seeking bereaved sample, using similar methods as Cozza et al. (17) and Mauro et al. (18), and concluded that ICD-11 PGD outperformed PGD-2009 (identifying 96% vs. 59% clinical cases). Importantly, the marker for ‘caseness’ used by Cozza et al. (17) and Mauro et al. (13, 18) sparked a debate in which scholars expressed serious methodological concerns about excluding people with scores between 20 and 30 on
the Inventory of Complicated Grief from the analyses and argued that distinguishing normal from pathological grief for these ‘borderline-cases’ is the real challenge (19, 20). In response, Cozza et al. (21) reanalysed their data including the borderline-cases and concluded that ICD-11 PGD and CG criteria outperformed DSM-5 PCBD and PGD-2009 criteria in terms of identifying ‘clinical caseness’.

Two studies have shown that applying diagnostic criteria for DSM-5 PCBD versus ICD-11 PGD results in substantially different findings in terms of prevalence and predictive validity. More specifically, prevalence rates were shown to be at least two times higher using the ICD-11 PGD criteria compared with DSM-5 PCBD criteria (22, 23). However, increasing the number of symptoms needed to meet ICD-PGD criteria to at least five accompanying symptoms improved agreement in prevalence rates between DSM-5 and ICD 11 pathological grief (23). Furthermore, people meeting (vs. not meeting) self-rated criteria for DSM-5 PCBD at baseline reported significantly higher pathological grief, depression, and posttraumatic stress symptom-levels one year later when controlling for baseline symptom-levels, whereas ‘caseness’ of self-rated criteria for ICD-11 PGD at baseline did not predict the intensity of these symptoms one year later (22).

It should be noted that most studies evaluating the psychometric properties of the diagnostic criteria sets for pathological grief used (a selection of) items that were similar to the diagnostic criteria that they intended to assess, but these items had not all been developed to assess these criteria. For instance, Mauro et al. (13) used one item (i.e., ‘Trouble accepting’) of the Structural Clinical Interview for CG to assess two ICD-11 PGD criteria (i.e., ‘Denial’ and ‘Difficulty accepting the death’) and Boelen et al. (22, 23) used items from a depression measure to assess some ICD-11 PGD and DSM-5 PCBD criteria. Moreover, certain measures that were developed to assess a specific criteria set of pathological grief (e.g., the Structural Clinical Interview for CG) are not well-validated; for instance,
psychometric properties were not evaluated across samples that differ with respect to cultural background, age, and mode of death. In addition, current measures used to assess pathological grief criteria differ in response scales (frequency vs. severity) and delivery format (survey vs. interview), which limits comparability of findings across studies. Lastly, comparability between prevalence rates and predictive validity across studies is also hindered due to the lack of a gold standard for defining ‘caseness’ of pathological grief, which in turn leads to differences in findings.

To overcome the limitations of prior comparative studies and to move the bereavement field forward, we propose the following two objectives. First, it is pivotal that researchers explicitly and consistently report which pathological grief criteria they have used in their study to avoid confusion or misinterpretation. As noted, research has indicated that different diagnostic criteria sets yield different prevalence rates and vary in terms of predictive validity. It is therefore not justified to generalise findings regarding prevalence rates and predictive validity across studies using different diagnostic criteria of pathological grief, and researchers should acknowledge this when interpreting their findings.

Second, it is essential for researchers to use instruments that are intended to assess diagnostic criteria of pathological grief when drawing conclusions about diagnostic performance. Empirical evidence regarding performance of diagnostic criteria sets of pathological grief is primarily based on self-report questionnaires, which may overestimate symptom levels (as shown in depression research (24)). Using clinical diagnostic interviews that tap into both DSM-5 PCBD and ICD-11 PGD diagnostic criteria, but ideally include all criteria sets, measured with uniform response scales, would allow researchers to overcome limitations of prior comparative studies and would allow a direct comparison of the diagnostic performance of the different diagnostic criteria sets for pathological grief. Furthermore, the performance of diagnostic criteria sets should be evaluated across different samples of
bereaved people, varying in terms of e.g., 1) mode of death, 2) age, 3) recruitment source (treatment-seeking vs. non-treatment-seeking people), 4) time frame since death, and 5) cultural background.

In sum, it is advised that researchers use clinical diagnostic interviews to further evaluate the validity and utility of pathological grief criteria. This could inform future updates of the psychiatric classification systems in which diagnostic criteria sets for pathological grief are harmonised. This is urgently needed in order to reach consensus on criteria that correctly identify bereaved people in need of professional support and, consequently, to prevent unnecessary pathologisation of grief reactions.
References


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Supplementary Material

Table 1. Similarities and differences between five diagnostic criteria sets of pathological grief

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>DSM-5 Persistent complex bereavement disorder (7)</th>
<th>ICD-11 Prolonged grief disorder (8)</th>
<th>Prolonged grief disorder – 2009 (9)</th>
<th>Complicated grief (10)</th>
<th>Beta-draft ICD-11 Prolonged grief disorder (15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Persistent yearning/longing for the deceased.</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Intense sorrow and emotional pain</td>
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<td>X</td>
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<td>Preoccupation with the deceased</td>
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<td>Preoccupation with the circumstances of the death</td>
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<tr>
<td>Marked difficulty accepting the death</td>
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<td>Experiencing disbelief/emotional numbness over the loss</td>
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<td>Difficulty with positive reminiscing about the deceased.</td>
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<td>Bitterness or anger related to the loss</td>
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<td>Maladaptive appraisals about oneself (e.g., self-blame)</td>
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<tr>
<td>Feeling that life is meaningless or empty without the deceased</td>
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<tr>
<td>Confusion about one’s role in life (e.g., feeling that a part of oneself died)</td>
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<td>Guilt</td>
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<td>Denial</td>
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<td>Blame</td>
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15
| Feeling envious of others who have not experienced a loss | X |
| Frequently experiencing pain or other symptoms that the deceased person had, or hearing the voice or seeing the deceased person | X |
| Experiencing intense emotional or physiological reactivity to memories of the person who died or to reminders of the loss | X |
| Change in behavior due to excessive proximity seeking (e.g., doing things that are reminders of the loss) | X |