Response to: Prolonged grief disorder for ICD-11: the primacy of clinical utility and international applicability

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We have read with interest the recent debate paper ‘Prolonged grief disorder for ICD-11: the primacy of clinical utility and international applicability’ by Killikelly and Maercker (2018). Establishing prolonged grief disorder (PGD) in the ICD-11 has been a long-anticipated development that is likely to provide a great impetus for research and treatment development for bereaved persons experiencing severe grief reactions. We appreciate the authors’ thorough historical analysis of the development of disorders for pathological grief and the clear explanation of the guiding principles in the establishment of the ICD-11 PGD criteria. We nevertheless disagree with two central claims made in this paper. Specifically, we take issue with assertions that prior research on a variety of qualitatively different precursor criteria for grief disorders (1) offers valid diagnostic guidelines for the inclusion of PGD in the ICD-11, and (2) confirms that the novel ICD-11 PGD criteria provide the same valid symptom structure as these precursor criteria.

A fundamental problem with the ICD-11 PGD criteria (World Health Organization, 2016) is the limited research conducted on these criteria and the lack of validated instruments to assess these criteria. Recent studies on grief disorders are predominantly based on previously proposed criteria for PGD (particularly PGD-1999; Prigerson et al., 1999; and sometimes PGD-2013; Maercker et al., 2013), complicated grief (CG; Shear et al., 2011), and persistent complex bereavement disorder (PCBD; DSM-5). In these studies, disordered grief has primarily been assessed with versions of the Inventory of Complicated Grief (e.g. ICG; Prigerson et al., 1995) or the Prolonged Grief 13 scale (PG-13, assessing PGD-2009; Prigerson et al., 2009). Diagnostic criteria and rules of precursor grief disorders, including PGD-2009 and PGD-2013, diverge substantially from those of ICD-11 PGD, and oft-used instruments for grief disorders [ICG(-R), PG-13] do not assess ICD-11 PGD criteria. It is therefore questionable whether previous studies cited by Killikelly and Maercker (2018) support the validity of ICD-11 PGD diagnostic guidelines.

Specifically, we have doubts as to whether studies cited on PGD’s prevalence (Lundorff, Holmgren, Zachariae, Farver-Vestergaard, & O’Connor, 2017; estimates based on varying diagnostic criteria, measures, and cut-offs), diagnostic performance (e.g. Maciejewski, Maercker, Boelen, & Prigerson, 2016; comparing PGD-2013 with other precursor criteria), distinctiveness from other disorders (e.g. Boelen, 2013; based on PGD-2009 criteria), central symptoms in network analyses (Robinaugh, LeBlanc, Vuletich, & McNally, 2014; based on PCBD criteria), and treatment effects (based on varying diagnostic criteria, measures, and cut-offs), generalize to, and thus support the validity of ICD-11 PGD criteria.

To illustrate this point, we will show that prevalence rates are likely to be much higher for ICD-11 PGD than for the precursor grief disorders that Killikelly and Maercker (2018) claim ICD-11 PGD is most similar to, namely PGD-2009 and PCBD. ICD-11 disorder definitions are based on a typological approach; there is no strict requirement for the number of symptoms needed to meet the diagnostic threshold. While Killikelly and Maercker (2018) argue that this will result in greater sensitivity of case identification, this is also likely to increase the risk of overdiagnosis. Despite the ICD-11 typological approach, two very recent studies have implemented a diagnostic algorithm to assess ICD-11 PGD. The algorithm holds that to meet PGD criteria one needs to experience persistent and pervasive longing for the deceased and/or persistent and pervasive cognitive preoccupation with the deceased, combined with any of 10 additional grief reactions presumed indicative of intense emotional pain. Mauro et al. (forthcoming) showed that in a treatment-seeking sample an approximation of ICD-11 PGD criteria (e.g. the symptoms ‘denial’ and ‘difficulty accepting the death’ were assessed with one item) categorized 95.8% of participants with distressing and impairing grief, whereas PGD-2009 criteria categorized only 59.0% in this group. Boelen et al. (2018) demonstrated that the prevalence of probable ICD-11 PGD (tapped with ICG-R and Beck
Depression Inventory-II items; 18.0%) was nearly three times that of PCBD (6.4%) in a community-based bereaved sample.

In summary, the establishment of ICD-11 PGD criteria appears to be an important step in helping people who experience severe grief reactions to receive appropriate treatments. However, the ICD-11 PGD criteria differ markedly from precursor grief disorder criteria, and pioneering empirical research suggests that ICD-11 PGD has qualitatively different characteristics from its precursors. Killikelly and Maercker’s (2018) claims that prior research supports the validity of ICD-11 PGD criteria, and that this disorder has the same valid symptom structure as PGD-2009 and PCBD, are therefore unfounded. Only systematic and well-designed empirical research can assess the validity and utility of this new grief disorder.

Disclosure statement
No potential conflict of interest was reported by the authors.

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