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Research paper

User acceptability of the diagnosis of prolonged grief disorder: How do professionals think about inclusion in ICD-11?

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ABSTRACT

Background: For the next edition of the *International Statistical Classification of Diseases* (ICD-11) it is proposed to include *prolonged grief disorder* as a new diagnosis. The diagnosis describes persistent intensive and disabling grief reactions to bereavement (WHO, 2016b). The aim of the present survey was to determine the extent to which the diagnosis is accepted by practitioners in the healthcare and psychosocial field.
Methods: A total of 2088 German-speaking professionals in the fields of psychotherapy, psychology, counselling, medicine and palliative care completed the online survey.
Results: 42.4% of the participants felt that the advantages of including the diagnosis outweigh the disadvantages, 32.9% came to the conclusion that there are more disadvantages. The remaining 24.7% stated that advantages and disadvantages are balanced. The proposed classification as separate diagnosis was supported by 24.8%, while 60.0% preferred alternatives (e.g. as subtype of adjustment disorder). Furthermore, a time criterion of at least 12 months was voted for considerably more frequently (49.2%) than the proposed 6 months (11.3%). Objections were predominantly expressed with regard to pathologization of normal grief and to the difficulty of adequate crosscultural application of the diagnosis.
Limitations: Results are limited to predominantly German health-care professionals. The items did not undergo psychometric analyses.
Conclusions: The disagreement about the diagnosis found in specialist literature is also reflected in the responses by the participants. The present results provide stimulation for future questions and validation studies carried out as part of the ICD revision.

1. Introduction

Since the mid 1990s, research efforts have increasingly been concerned with evaluating a distinct grief disorder. Various proposals of criteria have since been made for inclusion in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) and the ICD-11 (e.g. Horowitz et al., 1997; Prigerson et al., 2009; Shear et al., 2011). While in the German health care system diagnoses have to be coded according to ICD-10, the DSM-5 is often used additionally for research purposes (Fydrich, 2012). The relevant DSM-5 working group assessed the evidence for inclusion of a specific grief disorder as insufficient (APA, 2011c; as cited in Wakefield, 2012). As a result, *persistent complex bereavement disorder (PCBD)* has been included in the appendix of the DSM-5 as a condition for further study and in the section *other specified trauma- and stressor-related disorder* (APA, 2013). The DSM working group's proposal to include an *adjustment disorder related to bereavement* has not been adopted (APA, 2011c; as cited in Wakefield, 2012; Bryant, 2014). ICD-10 postulates encoding under adjustment disorders "grief reactions of any duration, considered to be abnormal because of their form or content" (WHO, 1992, p. 150). Whereby „normal bereavement reactions, appropriate to the culture of the individual concerned and not usually exceeding 6 months in duration" should be recorded by a Z-code. The ICD is currently being revised and the approval of the 11th edition is planned for 2018 (WHO, 2016a). In this context, the ICD-11 working group on stress-related disorders suggested the inclusion of *prolonged grief disorder* (PGD) as a separate diagnosis (Maercker et al., 2013a, 2013b). PGD is currently defined on the *ICD-11 Beta Draft* website as follows:

> Prolonged grief disorder is a disturbance in which, following the death of a … person close to the bereaved, there is persistent and pervasive grief response characterized by longing for the deceased

Abbreviations: PGD, prolonged grief disorder; PCBD, persistent complex bereavement disorder; F-diagnoses, diagnoses of mental disorders

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or persistent preoccupation with the deceased accompanied by intense emotional pain (e.g. sadness, guilt, anger, denial, blame, difficulty accepting the death, feeling one has lost a part of one's self, an inability to experience positive mood, emotional numbness, difficulty in engaging with social or other activities). The grief response has persisted for an atypically long period of time following the loss (more than 6 months at a minimum) and clearly exceeds expected social, cultural or religious norms for the individual's culture and context. Grief reactions that have persisted for longer periods that are within a normative period of grieving given the person's cultural and religious context are viewed as normal bereavement responses and are not assigned a diagnosis. The disturbance causes significant impairment in … important areas of functioning (WHO, 2016b).

The ICD-11 website currently provides the opportunity to register and assess the utility of the proposed diagnosis or to make comments on PGD (WHO, 2016b). The *ICD-11 Clinical Descriptions and Diagnostic Guidelines* (not specifying fixed criteria as it is the case in DSM-5) will finally include: a brief definition, essential features and additional sections e.g. about the boundary with normality and with other disorders, as well as course, developmental, culture-, and gender related features (First et al., 2015). WHO's *Global Clinical Practice Network* (2017) recently posted draft ICD-11 guidelines of PGD on their platform to get accessed and commented by network members. They currently contain essential features (providing almost the same information as the definition cited above), additional features as well as boundaries with normal bereavement, depressive disorder and PTSD.

According to the ICD-11 working group, the proposal is based on the perceived clinical need to afford those affected a specific, evidence-based treatment. It further makes reference to empirical results that found PGD to be a distinct and impairing condition that cannot adequately be described by established diagnoses. The inclusion should enable more accurate diagnostic indication and provision of targeted intervention (Maercker et al., 2013a, 2013b). There are various clinical trials supporting the efficacy of grief-specific cognitive behavioural treatment (Rosner, 2015). The time criterion is justified by the predictive power of the diagnosis from 6 months after the loss: satisfaction of PGD criteria (proposed by Prigerson et al., 2009) after 6–12 months is associated with significant impairments at 12–24 months. The ICD-11 proposal is based on the same named criteria by Prigerson et al. (2009), however, there are differences: while the current ICD-11 proposal requires a minimum symptom duration of 6 months, Prigerson et al. specified that at least 6 months have to be elapsed since the death. The latter criteria are more restrictive requiring separation distress and at least five of nine additional cognitive, emotional and behavioural symptoms. To meet the DSM-5 PCBD criteria, at least seven of 16 listed symptoms must have persisted for at least 12 months (6 months for children).

The *World Health Organization* (WHO) calls for a wide range of multidisciplinary contributions to the ICD revision (International Advisory Group for the Revision of ICD-10, 2011; WHO, 2016a). ICD-11 proposals are to be publicly reviewed, undergo field-testing, and be studied for their degree of acceptability and clinical utility (Maercker et al., 2013a; Reed, 2010). The user acceptability of a new diagnosis follows from confidence in its diagnostic validity and ease of use (First, 2010; First et al., 2004). An ICD-11 case study (Keeley et al., 2016) tested the application of proposed ICD-11 guidelines for stressrelated disorders. Clinicians (N = 1738) had to classify case vignettes of PGD and normative grief under ICD-10 vs. ICD-11 guidelines. While PGD was correctly recognized by most clinicians under ICD-11, a broad range of diagnoses was assigned under ICD-10. The false positive rate (assignment of a diagnosis to normative grief) was very high under ICD-10 (63%) as well as under ICD-11 (50%). The authors conclude that the addition of PGD affords clearer diagnostic decisions but also raise concerns regarding the differentiation from normal grief. Consequently, the ICD-11 working group specified the guidelines by adding a 6-months time criterion. This amendment is to be tested in the next phase of ICD-11 field trials. A literature-review investigating the knowledge and attitudes of professionals concerning complicated grief revealed a lack of consensus regarding the diagnosis but underlined the voiced need for training to assist persons affected (Dodd et al., 2017). The authors point to the "largely unidirectional nature of research on complicated grief, in which the voice of the practitioner remains largely unheard" (p. 1456).

The various proposals for grief-related diagnoses triggered a wide discussion in specialist literature. While there are good reasons for inclusion of such a diagnosis on the one hand, there are compelling arguments urging caution on the other. Advantages and disadvantages must be considered carefully (Stroebe et al., 2013).

Wakefield raises the most specific criticisms regarding the validity of current diagnostic proposals (Wakefield, 2012, 2013b). Concerns largely focus on differentiation from normal grief; a high risk of false positives and the pathologization of normal grief are of primary concern (Breen and O'Connor, 2007; Bryant, 2014; Collier, 2011; Dodd et al., 2017; Goodkin et al., 2005–2006; Lammer, 2014; Prigerson and Jacobs, 2001; Stroebe et al., 2000; Thieleman and Cacciatore, 2013; Wagner and Maercker, 2010; Wakefield, 2012, 2013b). PGD cannot be qualitatively differentiated from normal grief (Holland et al., 2009). "PGD is characterized by normal symptoms of grief that remain too intense for too long" (Maciejewski et al., 2016, p. 266). However, several authors regard specifying a timed cut-off value with scepticism. Many believe 6 months to be too short a criterion (Getz, 2012; Granek and O'Rourke, 2012; Thieleman and Cacciatore, 2013; Wakefield, 2012, 2013a, 2013b; Wittkowski and Scheuchenpflug, 2015). PCBD criteria in the DSM-5 require a minimum period of 12 months of persisting symptoms. There has been both criticism (Boelen and Prigerson, 2012) as well as support. While Wakefield believes 12 months to be too short still, he nevertheless regards this as more in accordance with findings on grief persistence (Wakefield, 2013a; 2013b, 2012). Some specialists argue that the diagnosis should not be given before the first anniversary of the loss has passed, supporting a criterion of 13 or 14 months (Horowitz et al., 1997; Paul, 2011; Worden, 2009). Based on a study on the course of grief, Wittkowski and Scheuchenpflug (2015) conclude that the diagnosis should include a time criterion of 2 years. Some consider the term *prolonged grief disorder* as confusing, as grief is usually prolonged (Shear, 2011–2012) and should not be standardized with regard to time (German Hospice and Palliative Association, 2016).

A further point of contention is whether the term should refer to the process of *grief* e.g. prolonged *grief* disorder or the event of *bereavement* e.g. persistent complex *bereavement* disorder (Maciejewski et al., 2016). Moreover, some argue that the symptoms can be described adequately by established diagnoses, thus eliminating the need to introduce a new category (Bonanno and Kaltman, 2001; Bryant, 2013). Another significant criticism concerns the transferability of the criteria to different cultures (Rosenblatt, 2013) and subgroups of bereaved (Thieleman and Cacciatore, 2013; Wagner 2013a, 2013b). PGD criteria by Prigerson et al. were originally validated through a study involving mainly elderly widowed persons from the US (2009). Statements on prevalence, however, vary widely depending on sample characteristics (Stroebe et al., 2013). Diagnostic criteria require the grief reaction to exceed expected cultural and social norms. In this context, however, the question arises how this can be recorded reliably (Boelen and Prigerson, 2013; Rosenblatt, 2013); and to what extent does it make sense to use such norms as guidelines (Harris, 2009-2010; Wakefield, 2013b; Wortman and Boerner, 2011)?

The diagnosis could contribute to emotional relief and utilisation of targeted interventions (Johnson et al., 2009) but it could also lead to social and personal stigmatization (Burke and Neimeyer, 2013; Miller, 2013; Stroebe and Schut, 2005–2006; Thieleman and Cacciatore, 2013). Some authors state a high potential for abuse inherent in the diagnosis (Wakefield, 2013a) and fear an increase in inadequate intervention (Thieleman and Cacciatore, 2013). A crucial problem is