



Review article

Prevalence of prolonged grief disorder in adult bereavement: A systematic review and meta-analysis



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ABSTRACT

Background: Prolonged grief disorder (PGD) is a bereavement-specific syndrome expected to be included in the forthcoming *ICD-11*. Defining the prevalence of PGD will have important nosological, clinical, and therapeutic implications. The present systematic review and meta-analysis aimed to estimate the prevalence rate of PGD in the adult bereaved population, identify possible moderators, and explore methodological quality of studies in this area.

Methods: A systematic literature search was conducted in PubMed, PsycINFO, Embase, Web of Science, and CINAHL. Studies with non-psychiatric, adult populations exposed to non-violent bereavement were included and subjected to meta-analytic evaluation.

Results: Fourteen eligible studies were identified. Meta-analysis revealed a pooled prevalence of PGD of 9.8% (95% CI 6.8–14.0). Moderation analyses showed higher mean age to be associated with higher prevalence of PGD. Study quality was characterized by low risk of internal validity bias but high risk of external validity bias.

Limitations: The available studies are methodologically heterogeneous. Among the limitations are that only half the studies used registry-based probability sampling methods (50.0%) and few studies analyzed non-responders (14.3%).

Conclusions: This first systematic review and meta-analysis of the prevalence of PGD suggests that one out of ten bereaved adults is at risk for PGD. To allocate economic and professional resources most effectively, this result underscores the importance of identifying and offer treatment to those bereaved individuals in greatest need. Due to heterogeneity and limited representativeness, the findings should be interpreted cautiously and additional high-quality epidemiological research using population-based designs is needed.

1. Introduction

The psychological and physiological reactions that follow the loss of a loved one are collectively known as grief. Most individuals go through a painful, but natural, grieving process where the intensity of grief-related distress typically decreases gradually over time (Jordan and Litz, 2014). Thus, although bereavement can be a highly stressful and significant life experience, most individuals have sufficient internal resources and external support to adequately cope with their grief and slowly readjust to a life without the deceased (Prigerson et al., 2009; Zisook and Shear, 2009). However, research has also shown that for a significant minority of bereaved individuals the grieving process is particularly complicated (e.g., Lichtenthal et al., 2011; Prigerson et al.,

2009; Simon et al., 2007). Instead of a decreasing intensity of grief-related distress, these individuals experience severe grief reactions that become abnormally persistent and increasingly debilitating across time (Jordan and Litz, 2014; Maercker et al., 2013; Prigerson et al., 2009).

Prolonged grief disorder (PGD) is a proposed diagnostic category intended to classify bereaved individuals who experience notable dysfunction for atypically long periods of time following a significant loss (Prigerson et al., 2009). Core symptoms include a pervasive yearning for the deceased or persistent preoccupation with the deceased accompanied by intense emotional pain (World Health Organization, 2016). Furthermore, PGD is characterized by difficulties in engaging in social or enjoyable activities, a reduced ability to experience positive mood, and difficulties accepting the death of the

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loved one (World Health Organization, 2016). A duration criteria of six months is proposed to ensure that natural grief reactions in the acute state following bereavement are not confounded with the syndrome of PGD (Prigerson et al., 2009). Research have found symptoms of PGD to be associated with impairment of the bereaved person's familial, social, and occupational functioning to a similar extent as found for other mental disorders, e.g., depression and post-traumatic stress disorder (Jordan and Litz, 2014; Maercker et al., 2013; Prigerson et al., 2009; Shah and Meeks, 2012).

The identification of PGD fostered the issue of whether to include the condition as an official mental disorder in the diagnostic manuals. In relation to recent revisions of both the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*; American Psychiatric Association, 2013) and the *International Classification of Diseases* (11th ed.; *ICD-11*; World Health Organization, 2016), working groups were established to investigate the validity, specificity, and treatability of PGD. While the group editing *DSM-5* initially embraced the possibility of including PGD as a mental disorder, the proposal was finally rejected in 2013 (Bryant, 2014; Rosner, 2015). However, a code diagnostically corresponding to prolonged grief problems – Persistent Complex Bereavement Disorder (PCBD) – was added in the Appendix as a candidate disorder demanding further study (American Psychiatric Association, 2013; Maciejewski et al., 2016). Currently, PGD remains proposed for inclusion in the forthcoming *ICD-11*, scheduled for release in 2018 (World Health Organization, 2016). Inclusion of PGD will initiate the application of the diagnosis in healthcare settings. However, a number of unanswered questions remain regarding the impact of PGD, including the prevalence of the disorder in the general population. To date, systematic reviews of PGD have addressed its predictors, its prevention, and the effect of interventions to reduce grief-related symptoms (e.g., Lobb et al., 2010; Rosner et al., 2010; Wittouck et al., 2011). So far, only a limited number of epidemiological studies have assessed the prevalence of PGD in general population samples, and, to the best of our knowledge, no systematic reviews combining and comparing the existing individual studies of PGD prevalence have yet been published.

With no clear-cut data regarding the prevalence of PGD, much published theory and research use rather arbitrary expressions, such as “a significant minority” (e.g., Jordan and Litz, 2014; Zisook et al., 2010), to describe the number of individuals experiencing severe complications following bereavement. However, healthcare services are in need of a more precise estimate of the prevalence of PGD in the general population. Preferably, this information should be provided before the diagnosis is introduced to allocate economic and professional resources most effectively. We therefore conducted a systematic review and meta-analysis with the aim of providing an estimate of the prevalence of PGD in the general adult bereaved population.

2. Methods

The present study was protocol-based and conducted in accordance with recommendations from the Cochrane Collaboration (Higgins and Green, 2011) and the guidelines for Meta-Analysis Of Observational Studies in Epidemiology (MOOSE) (Stroup et al., 2000). Prior to the review, the protocol was submitted to PROSPERO – an international prospective register for review protocols – in May 2016 (Lundorff et al., 2016; registration number: CRD42016038416). The methods and results are documented according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Liberati et al., 2009).

2.1. Data sources and search strategy

A systematic keywords-based search was undertaken using the bibliographic databases of PubMed, PsycINFO, Embase, Web of Science, and CINAHL. The search string consisted of a combination

of subject headings (MeSH terms) and free text (keywords) to reflect indexing differences between databases. Informed by the PICO approach (Sackett et al., 1997), keywords related to population (“prolonged grief disorder” OR “prolonged grief” OR “complicated grief” OR “traumatic grief” OR “pathological grief” OR “persistent complex bereavement disorder”) were combined with words related to indicator (bereave*[MeSH] OR grief*[MeSH] OR grieving OR mourn*[MeSH] NOT “psychological trauma” [MeSH] NOT “violent death*”) and outcome (prevalence [MeSH] OR frequency OR incidence [MeSH] OR proportion). Two authors independently performed the search throughout the period of May 2016.

2.2. Selection criteria

The review included epidemiological studies of individuals aged 18 years or older who suffered the loss of a loved one through mainly non-violent death causes. The outcome variable was prolonged grief, as assessed with a standardized, validated psychometric instrument. Studies had to discriminate between individuals with natural (below a stated cut-off) and prolonged grief reactions (above a stated cut-off) and provide a prevalence estimate of PGD in the sample. In alignment with the duration criteria for PGD, all included studies had to assess grief with a mean time of at least 6 months post-loss. The literature search was limited to papers published in English-language peer-reviewed journals. No limitation of publication date was applied.

Intervention and case studies were excluded, together with studies conducted on infants, children, adolescents (sample mean age < 18 years), healthcare professionals, individuals with personality disorders, and psychiatric in-/outpatient samples. Studies exclusively investigating deaths by suicide, murder, natural disasters, or terrorist attacks were also excluded due to additional dimensions associated with such losses, e.g., severe comorbidity and risk of first hand exposure (Brent et al., 2009; Dyregrov et al., 2015; Piper et al., 2001; Tal Young et al., 2012). Finally, studies focusing on other forms of loss unrelated to bereavement (e.g., divorce, major illness, migration, or unemployment) were excluded.

2.3. Screening procedures

Sources identified in the literature search were independently assessed for eligibility by two authors through a two-step process. The first screening was performed based on titles and abstracts, while full-text papers were retrieved and assessed in the second screening. After each screening, the two authors compared their results, discussed discrepancies, and negotiated a decision. Following each screening, interrater reliability was assessed using Cohen's Kappa statistic, κ (McHugh, 2012). Study screening was conducted using the online software Covidence (Veritas Health Innovation Ltd, 2016).

2.4. Risk of bias assessment

The included studies were systematically assessed for possible risk of bias (RoB) with a tool specifically developed for population-based prevalence studies (Hoy et al., 2012). This tool consists of ten items, including four items addressing external validity (i.e., representativeness of sample) and six items addressing internal validity (i.e., measurement reliability). The items are formulated as dichotomous ‘yes-no’ questions, for example “Was the same mode of data collection used for all subjects?”. Each item is scored with a value of 1 (yes) or 0 (no), yielding a RoB total score for each study with higher scores indicating lower RoB and higher methodological validity. In accordance with the guidelines, when a paper provided insufficient information to permit a judgment for a particular item, this item was rated high RoB (0 points) (Hoy et al., 2012). Studies with scores of 9 or 10 points (i.e., 9 or 10 ‘yes’-answers) were considered to have low RoB; studies with scores of 7 or 8 points were considered to have moderate RoB; and

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