Current research on prevalence of prolonged grief disorder is inadequate, says study

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Proper procedures for diagnosing prolonged grief disorder (PGD) are not being followed in research into its prevalence, according to a study published in *Harvard Review of Psychiatry*. What's more, most

published literature doesn't clearly acknowledge the limitations of the methodology used.

The lead investigator was Margaret S. Stroebe, Ph.D., a clinical psychologist at Utrecht University and the University of Groningen in the Netherlands. She and her colleagues elaborate, "Prevalences of PGD are based on self-reported symptomatology, with rates derived from percentages of bereaved persons reaching a certain cutoff score on a questionnaire, without clinical interviewing. This likely results in systematic overestimation of prevalences."

Formal procedures to establish the presence of PGD are becoming mandatory

Prolonged grief has been described as grief reactions that become abnormally persistent and cause significant impairment in daily functioning. PGD was added to the 11th edition of the "International Classification of Diseases (ICD-11)" in 2018 and to the 5th edition of the "Diagnostic and Statistical Manual of Mental Disorders" in its 2022 text revision (DSM-5-TR).

Neither handbook is a diagnostic instrument; they are simply classification systems, providing lists of key symptoms for various disorders. "It follows that diagnosis of disorder cannot be made on the basis either reaching a cutoff point on a self-report measure or scoring high on particular items designed to screen for symptoms according to DSM/ICD," Dr. Stroebe's group emphasizes. "Clinical interviews and judgment are imperative and serve to provide additional information to that provided in a questionnaire for developing a fuller understanding of the bereaved person's experience."

Yet when the researchers reviewed 22 peer-reviewed articles on the

prevalence of PGD, published between 2019 and 2023, they found that not one of them used interviews to establish the diagnosis. What's more, only eight of the articles explicitly highlighted—both in their titles/abstracts and discussion sections—the limitations of relying on self-reported ratings.

The problems identified in this analysis "equally apply to research focused on issues such as the phenomenological characteristics of PGD or the effects of interventions for people suffering from PGD," the research team believes.

Guidance for improvement in research—and in clinical practice

New self-report screening tools have been validated for identifying people at risk of PGD per ICD-11 and DSM-5-TR, including the Traumatic Grief Inventory–Self Report Plus and the International Prolonged Grief Disorder Scale. The authors say these instruments are cost-effective and time-efficient, but stress that reaching a self-report symptom cutoff point on a questionnaire is only suggestive of diagnostic status. The same is true of scoring high on self-report symptoms stated in a diagnostic handbook. Clinical judgment is needed to establish diagnostic status.

Dr. Stroebe and her colleagues provide guidance on factors to take into account.

"DSM-5-TR notes that among associated features of PGD that the clinician may need to consider are maladaptive cognitions, somatic complaints, and harmful health behaviors," they write. Other considerations are the availability of supportive resources and the bereaved person's life circumstances and cultural affiliation. "These

factors affect not only clinical diagnosis but also other consequential clinical decisions, such as those with respect to psychoeducation and treatment priorities."

More information: Margaret S. Stroebe et al, On the Classification and Reporting of Prolonged Grief: Assessment and Research Guidelines, *Harvard Review of Psychiatry* (2024). DOI: 10.1097/HRP.0000000000000389

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