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## Operationalization, implications and correlates of the cultural deviance criterion for ICD-11 and DSM-5 prolonged grief disorder

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### ABSTRACT



Prolonged Grief Disorder (PGD) is included in ICD-11 and DSM-5-TR and includes a requirement of cultural deviance. This study examined endorsement rates and factors associated with endorsement of this criterion among Danish bereaved spouses ( $n = 425$ ) and their adult children ( $n = 159$ ) four years post-loss. In total, 7.5% ( $n = 44$ ) participants endorsed this criterion. Both including and excluding the criterion, the prevalence rates for probable DSM-5-TR PGD were 1.4% ( $n = 8$ ) and 1.7% ( $n = 10$ ), respectively and for probable ICD-11 PGD were 1.4% ( $n = 8$ ) and 2.2% ( $n = 13$ ), respectively. Age and gender of the deceased, age of the bereaved, greater grief severity, and comorbid psychopathology were positively associated with endorsement of the criterion. Findings demonstrate low endorsement of the cultural deviation criterion, that its inclusion excludes several potential PGD cases, and unanticipated associations with several factors raise questions about the criterion's validity.

Despite being a normal and almost universal experience, the death of a loved one can be one of the most painful and devastating events in human life. For most people, the acute grief experienced in the aftermath of a loss lessens over time; nonetheless, increasing evidence indicates that a sizable minority of bereaved individuals have a protracted and debilitating grief response that is not best explained by any existing psychiatric diagnosis (e.g., Djelantik et al., 2020; Jordan & Litz, 2014; Lundorff et al., 2017; Prigerson et al., 2009; Rosner et al., 2021). Consequently, in the 11<sup>th</sup> version of the International Classification of Diseases (ICD-11; World Health Organization [WHO], 2022) and the text revision of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR; American Psychiatric Association [APA], 2022), Prolonged Grief Disorder (PGD) is included as a new grief-specific condition.

There are numerous parallels between the ICD-11 and DSM-5-TR formulations of PGD, but there are also several differences in terms of symptom count, content, and the consequent algorithm used to define caseness (for an overview see Eisma et al., 2022). Both

the ICD-11 and DSM-5-TR formulations share the unique requirement of cultural deviance, which states that the length and intensity of the grieving response must exceed what is regarded as typical according to one's social, religious, or cultural norms (Eisma, 2023). In ICD-11, this requirement is specified as "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*" (emphasis added). Similarly, in DSM-5-TR, it is specified as: "The duration and severity of the bereavement reaction clearly exceeds expected social, cultural, or religious norms for the individual's culture and context."

Since loss of loved ones are inevitable and the expression of grief is often tied to cultural, social, and religious norms, it has been argued that including cultural deviance as an extra diagnostic requirement of PGD is necessary to ensure that potential variability according to these factors are accurately accounted for (Reed et al., 2022). However, a potential issue with the inclusion of such a criterion is that both the ICD-

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11 and DSM-5-TR specify that it must be based on clinical assessment which poses a challenge for self-report-based surveys of this new disorder that per definition do not accommodate clinical evaluation. The Aarhus Prolonged Grief Disorder Scale (A-PGDs; O'Connor et al., 2023), a self-report-based measure of ICD-11 and DSM-5-TR PGD, includes an assessment of perceived cultural deviance by self and others as a proposed approximation of this cultural deviation diagnostic criterion. The A-PGDs schedule is the first self-report-based measure that can be used to assess both ICD-11 and DSM-5-TR PGD that explicitly includes items to assess cultural deviation. Previous measures that have included a cultural criterion question have focused on the ICD-11 diagnostic requirements only (e.g., International Prolonged Grief Disorder Scale; Killikelly et al., 2021), or have focused on symptoms of both disorders but failed to include a cultural criterion (e.g., The Traumatic Grief Inventory Self Report Plus (TGI-SR+; Lenferink et al., 2022). The A-PGDs is available in numerous languages and can be found online (<https://psy.au.dk/en/research/research-centres-and-units/unit-for-bereavement-research/researchers-and-professionals/resources-to-professionals>).

In the A-PGDS, cultural deviance of symptomatology is rated on two items assessing self-perceived cultural deviance and whether others have commented on a perceived deviant nature of the course of grief. The A-PGDs adopts a direct connection to concrete behaviors from the social network and/or to the respondent's own thoughts of the normality of their grief reaction. One notable strength of the A-PGDs is the ability to examine cultural deviance as perceived by others as well as by the individual. For example, a person may not consider their grief response to be culturally deviant, but they may report that others, like peers or family, have noticed that it is unusual. Notably, this approach has yet to be empirically tested. Moreover, because PGD represents the first axis-I disorder which implicitly includes cultural deviance as a diagnostic requirement, there is a dearth of studies on the implications of including a criterion of cultural deviance to a psychiatric diagnosis such as prolonged grief.

Consequently, the current study had two aims: Firstly, we aimed to study the endorsement rates of the cultural deviance criterion for prolonged grief via self-reporting of self- and other-perceived deviance and its consequences for prevalence rates of probable PGD. Secondly, we aimed to study what predicted endorsement of the cultural deviance criterion and the

associations between endorsing the criterion of cultural deviance and comorbid disorders of PGD.

## Methods

### Participants

Data for the present study was derived from The Aarhus Bereavement Study (TAB Study) which is an ongoing, longitudinal cohort study investigating grief trajectories in adults bereaved by the loss of a spouse or parent. Participants were identified from the Danish Civil Registration System containing information on all individuals, aged 18 years or above, who lost a spouse and lived in the metropolitan area of Aarhus in Denmark (Harris et al., 2023; Vang et al., 2022). Full procedural details of the TAB study have been described elsewhere (Harris et al., 2023; Vang et al., 2022). Data was collected at various intervals following the bereavement by postal or internet mail. This included two months post-loss (Wave 1), 6-months post-loss (Wave 2), 11-months post-loss (Wave 3), 18-months post-loss (Wave 4), 26-months post-loss (Wave 5), three-years post-loss (Wave 6), and four years post-loss (Wave 7). Data from Wave 7 was used for the current study. In total, 606 participants participated in Wave 7. Of those 606 participants, 22 were excluded due to excessive missing data on the A-PGDs (i.e., 41.6–100% missingness). Hence, 584 participants were included in the present study. The mean age of participants was 62.69 (SD = 14.29, Median = 66 years, Range = 18–86 years). More than two thirds of the sample being female (67.6%,  $n = 395$ ) and were the spouse of the deceased (72.8%,  $n = 425$ ). Demographic and mental health information from these participants were collected at Wave 1. Ethical approval for this study was obtained the local scientific ethical committee in Middle Jutland, Denmark (case number: 1-10-72-176-17).

### Measures

**Prolonged Grief Disorder:** The Aarhus Prolonged Grief Disorder Scale (A-PGDs; O'Connor et al., 2023) is a 20-item scale which assesses for symptoms of PGD as described in both the ICD-11 and DSM-5-TR. To reach the first aim of the study, the first nineteen items were used. Details on the development of the A-PGDs are described in full in the initial validation study (O'Connor et al., 2023). Briefly, the development of the A-PGDs was based on a number of steps: (1) an initial set of items were developed based on both the ICD-11 and DSM-5-TR descriptions of PGD,

(2) a panel of experts in PGD rated the items, evaluated item formulations, and assessed the proposed formats of the questionnaire in an open discussion format, (3) the comprehensibility and correct interpretation of each of the proposed items were tested in a focus group of bereaved adults, (4) items were reworded to ensure maximum clinical utility, and (5) the final items were translated from Danish to English.

The A-PGDs contains two items measuring the core symptoms of PGD included in both the ICD-11 and DSM-5-TR descriptions of PGD (i.e., *'longed for \_\_\_\_\_ during the past month?' 'preoccupied with thoughts of \_\_\_\_\_ even when you did not want to be thinking about them?'*) and the remaining items measure additional emotional symptoms (see Table 1 for emotional symptoms applicable to the ICD-11 and DSM-5-TR descriptions). One item measures functional impairment associated with the grief symptoms on a number of different functional domains (e.g., work, social, and family life). Participants rate symptom intensity using a 5-point Likert scale ranging from 'Not at all' (1) to 'Overwhelmingly' (5). Two additional items measure cultural deviance; one item requires participants to indicate if any of their acquaintances have expressed concerns regarding their grief reaction and another requires participants to indicate whether they themselves are concerned regarding their grief reaction either as compared to others surrounding them or their own perceptions regarding what constitutes "normal" grief (i.e., *"Are you worried about your own grief reaction, including that it is more severe or intense than you expected? (e.g., compared to the people you surround yourself with or what you think is normal";* item 19). Both items have 'Yes' (1) or 'No' (0) response formats. This response format was selected for the cultural deviance items due to this being considered most accessible for potential respondents. The cultural deviance item is considered fulfilled if the respondent answer "yes" to any of these two items.

The A-PGDs can be used to identify potential diagnostic cases or to capture symptom severity. Probable ICD-11 PGD requires endorsement of (1) one or more core symptoms (items 1 & 2: endorsement is Likert scale score  $\geq 4$ ), (2) one or more emotional symptoms (items 3 to 12: endorsement is Likert scale score  $\geq 4$ ), (3) functional impairment (item 17: endorsement is Likert scale score  $\geq 3$ ), (4) perceived cultural deviance ("yes" to items 18 or 19: either by self or others), and (5) the grief response must have been present during the preceding six months (item

20). Probable DSM-5-TR PGD requires endorsement of (1) one or more core symptoms (items 1 & 2: endorsement is Likert scale score  $\geq 4$ ), (2) three or more emotional symptoms (items 3, 5, 6, 9, 11–16: endorsement is Likert scale score  $\geq 4$ ), (3) functional impairment (item 17: endorsement is Likert scale score  $\geq 3$ ) and (4) perceived cultural deviance (items 18 & 19: either by self or other). Symptom severity can be computed by summing responses to the relevant symptoms for ICD-11 PGD (i.e., items 1–12) and DSM-5-TR PGD (i.e., items 1–3, 5–6, 9, 11–16). The internal consistency of the A-PGDs ICD-11 subscale ( $\alpha = .90$ ) and DSM-5-TR subscale ( $\alpha = .89$ ) was excellent in the present study.

Posttraumatic Stress Disorder (PTSD): The PTSD Checklist for DSM-5 (PCL-5; Weathers et al., 2013) is a twenty-item scale which assesses symptoms of PTSD as per the DSM-5 symptom criteria. For these items, participants rate how much they have been bothered by each of the symptoms in the past month using a 5-point Likert scale ranging from 'Not at all' (0) to 'Extremely' (4). A cutoff score of  $\geq 31$  was used to identify possible cases of DSM-5 PTSD. This cutoff has been shown to have adequate specificity (.95) and sensitivity (.85) for detecting cases of DSM-5 PTSD (Ashbaugh et al., 2016). The internal consistency of the PCL-5 ( $\alpha = .91$ ) was excellent in the present study.

Depression: The Center for the Epidemiological Studies of Depression Short Form (CES-D; Andresen et al., 1994) is a ten-item scale which assesses for symptoms of depression. For these items, participants rate the frequency at which they experienced each of the symptoms during the past week using a 4-point Likert scale ranging from "Rarely or none of the time" (0) to "All of the time" (3). A cutoff score of  $\geq 16$  was used to identify possible cases of depression. This cutoff has been shown to have adequate specificity (.75) and sensitivity (.76) for detecting cases of depression (Björngvinsson et al., 2013). The internal consistency of the CES-D ( $\alpha = .86$ ) was good in the present study.

Generalized Anxiety Disorder (GAD): The Generalized Anxiety Disorder Questionnaire (GAD-7; Spitzer et al., 2006) is a seven-item scale which assesses for symptoms of GAD as described in the fourth edition of the DSM (DSM-IV; APA, 1994). For these items, participants rate the frequency at which they experienced each of the symptoms over the last two weeks using a 4-point Likert scale ranging from "Not at all" (0) to "Nearly every day" (3). For the purposes of the present study, a cutoff score of  $\geq 10$  was

**Table 1.** Item-level descriptive statistics.

	Scale value					Mean (SD)	Range	Item-to-total Correlation DSM-5	Item-to-total Correlation ICD-11
	1	2	3	4	5				
	Not at all	A little	To some extent	Very much	Overwhelmingly	% Endorsed			
1. Have you longed for _____ during the past month?	13.6%	33.0%	29.9%	21.2%	2.2%	23.5%	1-5	.73***	.67***
2. Have you during the past month found yourself preoccupied with thoughts of _____ even when you did not want to be thinking about them?	26.1%	40.3%	23.5%	8.8%	1.2%	10.0%	1-5	.75***	.59***
3. Have you had feelings of sadness or sorrow during the past month?	38.8%	39.7%	17.4%	4.1%	0%	4.1%	1-4	.75***	.64***
4. Have you felt guilty during the past month?	74.5%	18.2%	6.2%	0.9%	0.2%	1.0%	1-5	.53***	.43***
5. Have you felt angry during the past month?	74.5%	17.6%	6.6%	1.4%	0%	1.4%	1-4	.72***	.38***
6. During the past month, has it been hard for you to believe that _____ is dead?	58.4%	26.1%	10.3%	4.6%	0.5%	5.2%	1-5	.74***	.55***
7. Have you blamed yourself for your loss during the past month?	7.9%	9.1%	2.6%	0.3%	0%	0.3%	1-4	.74***	.42***
8. During the past month, have you had trouble accepting that _____ is dead?	63.7%	23.3%	9.0%	3.5%	0.5%	4.0%	1-5	.69***	.56***
9. During the past month, have you felt that you have lost a part of yourself? (e.g., feeling as though a part of you has died)	63.6%	24.1%	8.8%	2.9%	0.7%	3.6%	1-5	.74***	.61***
10. During the past month, have you been unable to experience positive emotions?	74.5%	14.9%	7.8%	2.6%	0.2%	2.8%	1-5	.69***	.54***
11. During the past month, have you felt emotionally numb? (e.g., having difficulties with feeling emotions as you used to do, being emotionally stunned)	76.8%	16.1%	5.5%	1.2%	0.3%	1.6%	1-5	.69***	.53***
12. Have you had difficulty engaging in social or other activities during the past month?	68.7%	19.9%	7.8%	2.9%	0.7%	3.6%	1-5	.65***	.58***
13. Have you felt lonely during the past month?	43.0%	36.4%	13.5%	5.9%	1.2%	7.1%	1-5	.63***	.63***
14. During the past month, have you tried to avoid reminders that _____ is dead? (e.g., avoiding certain thoughts, feelings, places, music, conversation topics, etc. or keeping yourself constantly going)	84.9%	10.8%	3.1%	0.2%	0%	0.2%	1-4	.41***	.41***
15. During the past month, have you felt that life is meaningless since _____ has died?	78.7%	13.8%	5.0%	2.2%	0.2%	2.4%	1-5	.70***	.70***
16. Have you felt bitterness during the past month?	81.3%	13.8%	3.5%	1.0%	0.3%	1.4%	1-5	.60***	.60***
17. Overall, have these difficulties led to a decline in your level of functioning? (i.e., your ability to function in everyday life)	79.1%	16.3%	3.1%	1.6%	0%	4.6%	1-4	.60***	.60***
18. Have any of your acquaintances expressed concern about your grief reaction? (e.g., that they feel that it exceeds what they consider normal in relation to your social, cultural, or religious norms).						2.6%	0-1		
19. Are you worried about your own grief reaction, including that it is more severe or intense than you expected? (e.g., compared to the people you surround yourself with or what you think is normal).						5.9%	0-1		

Note: shaded numbers are those symptoms specific to ICD-11 and numbers in bold are those symptoms specific to DSM-5-TR.

used to identify possible cases of GAD. This cutoff score has been shown to have adequate sensitivity (.89) and specificity (.82) for detecting cases of GAD (Spitzer et al., 2006). In the present study, the internal consistency of the GAD-7 at Wave 7 was excellent ( $\alpha = .90$ ).

**Demographic variables:** Demographic variables included gender (male = 1, female = 2), age of participant (in years), and education (primary = 1, secondary = 2, tertiary = 3).

**Loss-related variables:** Loss-related variables included participant type (partner = 1, child = 2), gender of deceased (male = 1, female = 2), age of deceased (in years), and sickness prior to death (yes = 1, no = 2).

### Statistical analysis

First, item level statistics (including item endorsement rates, average scores on each item, range of scores, and item-to-total correlations) for the A-PGDs items (including functional impairment and the cultural deviation criterion) were calculated. Second, prevalence rates of probable DSM-5-TR PGD and probable ICD-11 PGD were calculated both including (cultural criterion included in diagnostic algorithm) and excluding (cultural criterion not included in the diagnostic algorithm) the cultural deviation criterion. Differences in the proportion of individuals that satisfied caseness for probable PGD based on the ICD-11 and DSM-5-TR criteria whether the cultural criterion was included or excluded were examined using chi-square tests of association and strength of associations were quantified using Cramer's  $V$  ( $\leq 0.2 =$  weak,  $0.2 - 0.6 =$  moderate,  $> 0.6$  strong). Third, multiple chi-square tests of association were conducted to examine the association between (1) demographic and loss-related predictors and meeting the cultural deviation criterion, (2) PGD symptom endorsement and meeting the cultural deviation criterion, and (3) mental health correlates and meeting the cultural deviation criterion. The strength of the associations was quantified using Cramer's  $V$  ( $\leq 0.2 =$  weak,  $0.2 - 0.6 =$  moderate,  $> 0.6$  strong). Adjusted standardized residuals  $\geq 1.96$  for cells in the cross-tabulations were used to assess significant differences between the observed and expected counts. Prior to conducting all chi-square tests of association analyses, we confirmed that all expected frequencies were greater than or equal to five and all levels of the variables were mutually exclusive, thus supporting the use of these tests (McHugh, 2013). Several independent samples t-tests

were conducted to examine association between continuous variables (i.e., age of bereaved, age of deceased, PGD summed scores) and meeting the cultural deviation criterion. Levene's test of equality of variance was violated for each of the continuous variables and therefore, a t statistic not assuming homogeneity of variance was computed. The strength of these associations was quantified using Cohen's  $D$  ( $< 0.40 =$  small,  $0.40 - 0.80 =$  moderate,  $> .80 =$  large) (Cohen et al., 2013).

## Results

### Item level statistics for the A-PGDs items

Item level statistics for all A-PGDs items are presented in Table 1. The most commonly endorsed PGD symptoms for the overall sample were item 1 'Have you longed for \_\_\_ during the past month?' (DSM-5-TR & ICD-11: 23.5%), item 2 'Have you during the past month found yourself preoccupied with thoughts of \_\_\_ even when you did not want to be thinking about them?' (DSM-5-TR & ICD-11: 10.0%), and item 13 'Have you felt loneliness during the past month?' (DSM-5-TR: 7.1%). Self-reported endorsement rates of the cultural deviation criterion by the self was 5.9% ( $n = 34$ ) and for others was 2.6% ( $n = 15$ ). Only 0.9% ( $n = 5$ ) of participants endorsed both the cultural deviation by the self and for others.

### Prevalence of probable DSM-5-TR PGD and probable ICD-11 PGD

In this sample, 1.4% (95% CI 0.5, 2.6;  $n = 8$ ) met caseness for probable DSM-5-TR PGD when the cultural deviation criterion was applied and 1.8% (95% CI 0.7, 3.1;  $n = 10$ ) met caseness for probable DSM-5-TR PGD when the cultural deviation criterion was not applied. Conversely, 1.5% (95% CI 0.5, 2.6;  $n = 8$ ) met caseness for probable ICD-11 PGD when the cultural deviation criterion was applied and 2.5% (95% CI 1.2, 3.8;  $n = 13$ ) met caseness for probable ICD-11 PGD when the cultural deviation criterion was not applied. There were significantly more participants who met caseness for probable DSM-5-TR PGD when the cultural criterion was not applied (1.9%,  $n = 10$ ) who also met caseness for probable ICD-11 PGD,  $\chi^2(1) = 399.186$ ,  $p < .001$ , and the effect size was large ( $V = .87$ ). There were also significantly more participants who met caseness for probable DSM-5-TR PGD when the cultural criterion was applied (1.5%,  $n = 8$ ) who also met caseness for probable ICD-11 PGD,  $\chi^2(1) =$

522.000,  $p < .001$ , and the effect size was large ( $V = 1.00$ ).

### Correlates of cultural deviation criterion endorsement

Given the slight increase in rates of probable caseness of both DSM-5-TR and ICD-11 PGD when the cultural deviation criterion was excluded, further analyses were conducted to determine the correlates of endorsing the cultural deviation criterion regardless of diagnostic status (i.e., whether a participant qualified for probable caseness of DSM-5-TR and/or ICD-11 PGD).

### Demographic and loss-related correlates

As demonstrated in Table 2, none of the demographic and loss-related correlates were significantly associated with endorsement of the cultural deviation criterion except for gender of the deceased,  $\chi^2(1) = 6.681$ ,  $p < .05$ , and the effect size was small ( $V = .11$ ). Specifically, significantly more participants endorsed the cultural deviation criterion when the deceased was female (adjusted standardized residual = 2.6).

As previously mentioned, two independent samples  $t$ -tests were conducted to examine the association between age of bereaved and endorsement of the cultural criterion according to participant type (i.e., spouse or child). For the spousal group, there was a significant association between age and endorsement of the cultural deviation criterion with younger adults ( $M = 62.69$ ,  $SD = 12.26$ ) being more likely to endorse this item as compared to older adults ( $M = 69.73$ ,  $SD = 8.94$ ),  $t(33.74) = 3.18$ ,  $p = .002$ ,  $d = .76$ . No statistically significant association was observed between

age and endorsement of the cultural deviation criterion for the child group,  $t(157) = 0.55$ ,  $p = .340$ . Finally, an independent samples  $t$ -test was conducted to examine the association between age of deceased and endorsement of cultural deviation criterion. Findings demonstrated those who reported age of deceased as being younger ( $M = 66.23$ ,  $SD = 11.84$ ) were more likely to endorse the cultural deviation criterion than those who reported age of deceased as being older ( $M = 72.66$ ,  $SD = 9.47$ ),  $t(582) = 4.25$ ,  $p < .001$ ,  $d = .67$ .

### Differences in A-PGDs symptom endorsement and severity

As demonstrated in Table 3, all A-PGDs items were significantly associated with endorsement of the cultural deviation criterion, except for item 4 "Have you felt guilty during the past month?" (ICD-11), item 10 "During the past month, have you been unable to experience positive emotions?" (ICD-11) and item 14 "During the past month, have you tried to avoid reminders that \_\_\_ is dead?" (DSM-5-TR). For the remaining items, which were significantly associated with endorsement of the cultural deviation criterion, the magnitude of these effects were largest for item 17 "Overall, have these difficulties led to a decline in your level of functioning" (DSM-5-TR & ICD-11:  $V = .31$ ) which constitutes the functional criterion of PGD with a yes/no response.

Findings from independent samples  $t$ -tests examining association between sum scores of PGD (ICD-11 and DSM-5-TR) and endorsement of cultural deviation criterion demonstrated that those who endorsed the cultural deviation criterion had higher ICD-11

**Table 2.** Crosstabulation of cultural deviation endorsement by demographic and loss-related characteristics.

	$\chi^2$ (df)	ES	Cultural criterion					
			Cultural criterion met			Cultural criterion not met		
			Observed count	Expected count	Adjusted residual	Observed count	Expected count	Adjusted residual
<b>Gender</b>	1.588 (1), $p = .208$	–						
Male			18	14.2	1.3	171	174.8	–1.3
Female			26	29.8	–1.3	369	365.2	1.3
<b>Education</b>	0.692 (2), $p = .708$	–						
Primary			8	8.4	–0.2	105	104.6	0.2
Secondary			14	11.7	0.8	143	145.3	–0.8
Tertiary			21	22.9	–0.6	287	285.1	–0.6
<b>Participant type</b>	0.000 (1), $p = .994$	–						
Partner			32	32	0.0	393	393	0.0
Child			12	12	0.0	147	147	0.0
<b>Gender of deceased</b>	6.681 (1), $p < .05$	.11**						
Male			23	30.6	–2.6	383	375.4	2.6
Female			21	13.4	2.6	157	164.6	–2.6
<b>Sickness</b>	0.112 (1), $p = .737$	–						
Yes			34	33.1	0.3	399	399.9	–0.3
No			10	10.9	–0.3	133	132.1	0.3



**Table 3.** Crosstabulation of cultural criterion endorsement by A-PGDs symptom endorsement.

	Cultural criterion							
	$\chi^2$ (df)	ES	Cultural criterion met			Cultural criterion not met		
			Observed counts	Expected counts	Adjusted residual	Observed counts	Expected counts	Adjusted residual
1. Have you longed for _____ during the past month?	11.07 (1), $p < .001$	.14***	19	10.1	3.3	117	125.9	-3.3
2. Have you during the past month found yourself preoccupied with thoughts of _____ even when you did not want to be thinking about them?	16.44 (1), $p < .001$	.17***	12	4.3	4.1	46	53.7	-4.1
3. Have you had feelings of sadness or sorrow during the past month?	31.96 (1), $p < .001$	.24***	9	1.8	5.7	15	22.2	-5.7
4. Have you felt guilty during the past month?	0.72 (1), $p = .397$	.04*	1	0.5	0.8	5	5.5	-0.8
5. Have you felt angry during the past month?	10.35 (1), $p < .001$	.13***	3	0.6	3.2	5	7.4	-3.2
6. During the past month, has it been hard for you to believe that _____ is dead?	11.75 (1), $p < .001$	.14***	7	2.2	3.4	23	27.8	-3.4
7. Have you blamed yourself for your loss during the past month?	5.15 (1), $p < .05$	.09*	1	0.2	2.3	1	1.8	-2.3
8. During the past month, have you had trouble accepting that _____ is dead?	17.79(1), $p < .001$	.18***	7	1.7	4.2	16	21.3	-4.2
9. During the past month, have you felt that you have lost a part of yourself? (e.g., feeling as though a part of you has died)	38.84 (1), $p < .001$	.26***	9	1.6	6.2	12	19.4	-6.2
10. During the past month, have you been unable to experience positive emotions?	2.88 (1), $p = .090$	.07	3	1.2	1.7	13	14.8	-1.7
11. During the past month, have you felt emotionally numb? (e.g., having difficulties with feeling emotions as you used to do, being emotionally stunned)	45.33 (1), $p < .001$	.28***	6	0.7	6.7	3	8.3	-6.7
12. Have you had difficulty engaging in social or other activities during the past month?	38.58 (1), $p < .001$	.26***	9	1.6	6.2	12	19.4	-6.2
13. Have you felt lonely during the past month?	52.80 (1), $p < .001$	.30***	15	3.1	7.3	26	37.9	-7.3
14. During the past month, have you tried to avoid reminders that _____ is dead?	0.08 (1), $p = .774$	.01	0	0.1	-0.3	1	0.9	0.3
15. During the past month, have you felt that life is meaningless since _____ has died?	26.14 (1), $p < .001$	.21***	6	1.0	5.1	8	13.0	-5.1
16. Have you felt bitterness during the past month?	34.82 (1), $p < .001$	.25***	5	0.6	5.9	3	7.4	-5.9
17. Overall, have these difficulties led to a decline in your level of functioning? (i.e., your ability to function in everyday life)	54.63 (1), $p < .001$	.31***	12	2.1	7.4	15	24.9	-7.4

PGD scores ( $M = 27.74$ ,  $SD = 8.52$ ) compared to those who did not ( $M = 18.78$ ,  $SD = 5.70$ ),  $t(45.19) = -6.77$ ,  $p < .001$ ,  $d = 1.24$ . Similarly, those who endorsed the cultural deviation criterion had higher DSM-5-TR PGD scores ( $M = 28.79$ ,  $SD = 8.77$ ) compared to those who did not ( $M = 18.91$ ,  $SD = 5.70$ ),  $t(43.83) = -7.18$ ,  $p < .001$ ,  $d = 1.34$ .

#### **Differences in psychopathological comorbidities**

As demonstrated in Table 4, there was a significant association between endorsing the cultural deviation criterion and meeting probable caseness for depression,  $\chi^2(1) = 25.031$ ,  $p < .001$ , GAD,  $\chi^2(1) = 57.595$ ,  $p < .001$ , and PTSD,  $\chi^2(1) = 37.818$ ,  $p < .001$ . These effects were all moderate ( $V = .22 - .32$ ).

#### **Discussion**

The objectives of the current study were to (1) examine the endorsement rates of the cultural deviance criterion for prolonged grief as defined by self and other-perceived deviance and its implications for prevalence rates of probable PGD and (2) identify factors associated with endorsement of the cultural deviance criterion and examine the association between endorsing the criterion of cultural deviance and comorbid disorders of PGD.

Compared to previous research where 5.5% to 14.6% of bereaved individuals endorsed the cultural deviation criterion included in the IPGDS (Shevlin et al., 2023), findings demonstrated that of the overall sample, 7.7% reported either self- or other-perceived cultural deviance, with 5.9% of those reporting self-

**Table 4.** Crosstabulation of cultural criterion endorsement by diagnostic status of depression, GAD, and PTSD.

	Cultural criterion								
	N (%)	$\chi^2$ (df)	ES	Cultural criterion met			Cultural criterion not met		
				Observed counts	Expected counts	Adjusted residual	Observed counts	Expected counts	Adjusted residual
Depression	27 (5.1%)	25.031 (1), $p < .001$	.22***	9	2.1	5.0	18	24.9	-5.0
GAD	30 (5.4%)	57.595 (1), $p < .001$	.32***	13	2.3	7.6	17	27.7	-7.6
PTSD	8 (1.6%)	37.818 (1), $p < .001$	.27***	5	0.6	6.1	3	7.4	-6.1

and 2.6% reporting other-perceived. Comparing the endorsement rates in the current study with those of studies utilizing alternative measures of PGD is difficult. It should be noted however that the IPGDS uses a single item to assess cultural deviation (Killikelly et al., 2021) whereas the A-PGDs schedule assesses cultural deviance both from a self- and other-perceived perspective. Also, the IPGDS uses a 5-point Likert scale to assess cultural deviation whereas the A-PGDs schedule uses a dichotomous response format. Moreover, Shevlin et al. (2023) included a sample who varied in their time since loss and had experienced various loss types. Hence, it is possible that endorsement of the cultural deviation criterion is partly explained by bereavement-related factors, and this requires further exploration.

Compared to prior studies where rates of probable DSM-5-TR PGD ranged from 3.3% to 17.8% (Boelen & Lenferink, 2020; 2022; Rosner et al., 2021) and rates of probable ICD-11 PGD ranged from 2.4% to 38.7% (Killikelly et al., 2021), the prevalence of PGD was notably lower in the present study. Specifically, when the cultural deviance criterion was applied, 1.4% and 1.5% met the criteria for probable DSM-5-TR and ICD-11 PGD, respectively. There are several potential explanations for the lower rates observed in the present study. First, the TAB study is a population-based study which includes a highly particular bereavement population who all experienced their loss within a similar time period (i.e., four years) and who were recruited from the same area (i.e., metropolitan area of Aarhus in Denmark). Conversely, other studies have included non-population-based samples to estimate prevalence of probable DSM-5-TR PGD (e.g., Boelen & Lenferink, 2020) and probable ICD-11 PGD (e.g., Killikelly et al., 2021). Second, several of the aforementioned studies utilized measures not specifically designed to capture the symptom content of PGD as described in the ICD-11 or DSM-5-TR models (e.g., Boelen & Lenferink, 2020), others used measures which do not include an assessment of cultural deviance (e.g., Rosner et al., 2021), while some have excluded the cultural criterion from the estimation of prevalence rates (Killikelly et al., 2021). Third, the

current study examined rates of DSM-5-TR and ICD-11 PGD approximately four years post-loss in a general population sample, with research demonstrating a significant reduction in the prevalence of probable PGD across time (e.g., Lunderoff et al., 2021).

Nevertheless, findings from the present study indicate a high level of concordance between rates of ICD-11 and DSM-5-TR PGD when assessed using the A-PGDs, which contrasts with other studies using alternative measures which have reported markedly divergent rates of ICD-11 and DSM-5-TR PGD in samples of bereaved adults, the majority of whom have experienced traumatic loss (e.g., Boelen & Lenferink, 2020). Prevalence rates of probable ICD-11 and DSM-5-TR PGD were also estimated without the cultural deviation criterion applied, with the prevalence of probable DSM-5-TR PGD increasing to 1.8% (an increase of 22%) and prevalence of probable ICD-11 PGD increasing to 2.5% (an increase of 40%). Overall, these findings suggest that although the cultural deviance criterion may improve the specificity of the diagnosis by reducing the number of people who meet probable caseness for PGD, its inclusion also omits several potentially meaningful PGD cases.

The second objective of the present study was to identify the characteristics of individuals who endorsed the cultural deviation criterion. Consistent with well-established risk factors of pathological grief responses (e.g., Burke & Neimeyer, 2013; Lobb et al., 2010), findings demonstrated that only gender of the deceased, younger age of the deceased, and younger age of bereaved spouses were associated with endorsement of the criterion. Given that it shares risk factors with other PGD symptoms, this may suggest that the cultural deviation criterion is a pertinent component of PGD. However, because the cultural deviation criterion is associated with similar risk factors to other PGD symptoms, and that it may be very difficult to estimate accurately in self-report questionnaires as well as in single-point clinical interviews, it may be very problematic to use cultural deviation as an independent criterion that on its own can determine whether an individual is eligible for diagnosis of PGD. It may be that cultural deviance should be considered

as one of the many associated symptoms rather than a diagnostic criterion, at least when included in self-report-based measures. Alternatively, the positive association between the predictors and endorsement of the cultural deviation criterion might suggest that variables other than an individual's cultural or religious background impact this criterion, thus undermining its utility.

This study also sought to examine the association between endorsement of the cultural deviation criterion and both PGD symptom endorsement and severity. Findings demonstrated that endorsement of the cultural criterion was positively associated with endorsement of all A-PGDs items, except for guilt (ICD-11 symptom only), inability to experience positive emotions (ICD-11 symptom only), and avoidance of reminders of the deceased (DSM-5-TR symptom only). There are (at least) two potential implications associated with these null associations. First, should the inclusion of a cultural deviation criterion within the PGD diagnoses be justified, this would challenge the necessity of the symptoms related to guilt, avoidance, and the incapacity to feel positive emotions as indicators of PGD. Indeed, prior research has evidenced low rates of endorsement of the DSM-5-TR avoidance symptom (e.g., Boelen, 2021; Boelen & Lenferink, 2022) and the ICD-11 symptoms of guilt and inability to experience positive emotions (e.g., Killikelly et al., 2021; Shevlin et al., 2023). Hence, it is possible that these symptoms are less relevant to the experience of the bereaved population. Alternatively, should these symptoms be considered as accurate indicators of PGD, this would challenge the necessity of the cultural criterion since it does not relate to the rarest and therefore most deviant symptoms of grief in the current sample (i.e., guilt, inability to experience positive emotions, and avoidance of reminders of the deceased). Finally, and consistent with prior research indicating high levels of comorbidity between symptoms of PGD and other disorders (for review see Komischke-Konnerup et al., 2021), this study found that those who endorsed the cultural deviation criterion were more likely to also meet probable caseness for depression, GAD, and PTSD than those who did not.

Taken together, this study seems to raise more questions than it answers. The findings support that the cultural deviation criterion defined as either others or self being concerned about the severity of the grief reaction is closely related to other symptoms of PGD, and that fulfillment of this criterion is related to a significantly higher level of overall PGD symptoms.

However, a high percentage of cases that may be highly clinically relevant are excluded when culture criterion is taken into account, especially in ICD-11. It is possible that the requirement for only one associated symptom in the ICD-11 formulation of PGD accounts for this greater discrepancy. The ICD-11 adopts a typological approach whereby a definition of the disorder and essential features are listed but not necessarily specific symptoms and probable caseness (Cloitre et al., 2018). This typological approach has been criticized due to the lack of transparency surrounding the most appropriate diagnostic algorithm to detect probable ICD-11 PGD, and hence, it has been suggested that research varying the number of core and associated symptoms is necessary to determine the optimal ICD-11 PGD criteria (Eisma et al., 2020). The exclusion of potentially clinically relevant cases when culture is introduced may lead to increased false negatives. Hence, the cost of adding this criterion may be too high and will likely be borne primarily by bereaved people who will not receive the support they need in the absence of a diagnosis. It is possible that the bereaved population's inadequate understanding of what cultural deviation actually is contributes to the low endorsement of the cultural deviation criterion and, consequently, the omission of several potentially significant cases when this criterion is included. Future research should focus on investigating the level of understanding that bereaved people have surrounding what is considering a typical grief response in their cultural and religious context. This study also calls into question whether cultural deviance is better understood as one of the associated symptoms of PGD rather than an independent diagnostic criterion for diagnosis. Specifically, because this criterion shares risk factors with other PGD symptoms, it may be more useful to consider cultural deviance as an additional PGD symptom rather than as a criterion.

Another issue raised by this study is whether the cultural criterion is possible to quantify and use in self-report-based measures. The only other diagnostic construct which includes cultural deviance as a diagnostic requirement are personality disorders (APA, 2013, p.645; ICD-11, 2022). It has been noted that understanding cultural values, customs, social conventions, and interactional patterns is becoming increasingly important in the assessment and treatment of mental disorders, particularly personality disorders (Ronningstam et al., 2018). Because personality disorders require such extensive clinical evaluation to recognize the saliency of cultural factors, it may be that

the same is required for PGD. It is essential that a clinician-administered diagnostic measure is developed to assess PGD as per both the ICD-11 and DSM-5-TR definitions, with a particular emphasis on how best to approach the cultural deviation requirement. It is advised that cultural evaluations of grief concentrate on learning about the patient's cultural practices related to dying, bereavement, and mourning, as well as on asking for support and coping with the loss of a loved one (Smid et al., 2018). Finally, the ICD-11 states that the grief response must persist "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" (WHO, 2018). This implies that the time criterion and cultural deviance criterion are interdependent. However, given that the current study raised concerns regarding the cultural deviance criterion, including this as a screener question in addition to the time criterion would be premature at this point.

This study has several limitations. First, data was derived from the seventh wave of a longitudinal cohort study investigating trajectories of grief approximately four years post-loss. Studies has repeatedly shown a considerable reduction in PGD symptoms over time (e.g., Shevlin et al., 2023), and therefore, it is probable that most participants in the current research are displaying normal grief. The second limitation of the present study is the low endorsement of several A-PGDs items which may have prohibited the detection of statistically significant effects. Third, findings from the present study are based on self-report data, which can lead to biased responding. Hence, replication using clinician-administered measures is paramount. This could be especially important for the cultural deviation criterion where it is possible that some individuals may lack awareness as to whether their grief response exceeds what is considered typical according to the societal and cultural norms and considering that the diagnostic criterion is clinician rated cultural deviance of symptomatology. Finally, the low prevalence rates of PGD overall as well as the low endorsement of the cultural deviation criterion precluded the conduction of a multiple logistic regression to the relative importance of the correlates. This is a matter which warrants exploration in future studies.

Overall, it is evident that research into the validity of the cultural deviation criterion is still in its infancy and that much remains to be learned about the meaningfulness, usefulness, and ramifications of such a criterion. The results of this study demonstrate that the

exclusion of the cultural deviation criterion has some impact on the prevalence of probable ICD-11 and DSM-5-TR PGD. Moreover, the cultural deviation criterion is linked to several significant characteristics, such as severity, impairment, and comorbidity. Although there is a growing body of research pertaining to the epidemiology and validity of PGD, the cultural deviation criterion is a matter which requires extensive exploration going forward. This is especially important for samples where the prevalence of PGD may be rather high, therefore whether the cultural criterion is included may have an important influence on the prevalence of the disorder.

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