



Further evaluation of the factor structure, prevalence, and concurrent validity of DSM-5 criteria for Persistent Complex Bereavement Disorder and ICD-11 criteria for Prolonged Grief Disorder

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ABSTRACT

Persistent complex bereavement disorder (PCBD) is a disorder of grief included in DSM-5. Prolonged grief disorder (PGD) is included in ICD-11. Few studies have evaluated and compared criteria sets for DSM-5 PCBD and ICD-11 PGD. The current study explored and compared the dimensionality, prevalence rates, diagnostic agreement, concurrent validity, and socio-demographic and loss-related correlates of both criteria sets. Self-reported data were available from 551 bereaved individuals. Confirmatory factor analysis showed that for DSM-5 PCBD-symptoms, a three-factor model with distinct but correlated factors fit the data well; for ICD-11 PGD-symptoms a one-factor model yielded adequate fit. The prevalence of probable DSM-5 PCBD (8.2%) was significantly lower than ICD-11 PGD (19.2%). Both DSM-5 PCBD and ICD-11 PGD were significantly associated with concurrent overall grief and depression, and varied as a function of education and time since loss. ICD-11 PGD prevalence rates went down and agreement with PCBD-caseness went up, when heightening the number of symptoms required for an ICD-11 PGD diagnosis. This study was limited by its reliance on self-reported data and grief symptoms were derived from two scales. That notwithstanding, findings provide further evidence that differences exist between disturbed grief criteria in DSM-5 and ICD-11 that may negatively impact research and care.

1. Introduction

In a significant minority of bereaved people, grieving symptoms become chronically disabling and distressing. This is now formally recognized with the inclusion of persistent complex bereavement disorder (PCBD) in DSM-5 (APA, 2013) and prolonged grief disorder (PGD) in ICD-11 (WHO, 2018). PCBD in DSM-5 and PGD in ICD-11 are similar in some ways (e.g., separation distress as hallmark symptom) but significantly different in others (e.g., more complex diagnostic algorithm and higher symptom threshold for PCBD). Ideally, criteria sets for both conditions are similar in terms of prevalence rates, dimensionality, and validity. This is important for theoretical reasons, for research findings (e.g., on prevalence and treatment effects) obtained using one set to be generalizable to the other, and, perhaps more so, for clinical reasons, to make sure that people with persistent impairing grief are rightfully identified as such, irrespective of the diagnostic system used. One recent study among adults (Boelen et al., 2018) compared the two

diagnostic sets included in DSM-5 and ICD-11, respectively, and found that these differed in terms of prevalence rates (with lower rates for PCBD compared to ICD-11 PGD) and predictive validity (PCBD-caseness but not ICD-11 PGD-caseness predicted mental health impairments).

More knowledge is needed about the discordance/concordance of the two criteria sets across different bereaved samples, recruited from different sources. Accordingly, the current study was designed to further explore (i) the dimensionality, (ii) prevalence rates and diagnostic agreement, (iii) concurrent validity, and (iv) socio-demographic and loss-related correlates of PCBD and PGD criteria sets. Additionally, in an attempt to explore whether the low diagnostic agreement found earlier was due to the low symptom threshold for a diagnosis of PGD, we examined (v) whether PGD prevalence decreased and agreement with PCBD improved when the symptom threshold for PGD caseness was heightened. Our prior study relied on data recruited via people offering advice and/or care to bereaved people (Boelen et al., 2018); the current study combined data from two earlier studies in which bereaved people

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were recruited via announcements on the internet (Boelen and Van den Hout, 2008; Boelen and Klugkist, 2011) thus allowing us to examine the generalizability of our prior findings.

Other criteria sets for disturbed grief have been proposed in the literature; these include Prigerson et al.'s (2009) criteria for prolonged grief disorder, criteria for complicated grief proposed by Shear et al. (2011), and a preliminary version of the current ICD-11 criteria (encompassing seven symptoms) proposed by Maercker et al. (2013). Prior studies have been conducted comparing these sets; these have shown that, among other things, Prigerson et al.'s criteria (2009) and DSM-5 criteria for PCBD yield similar prevalence rates (e.g., Boelen and Smid, 2017; Maciejewski et al., 2016) and that criteria proposed by Shear et al. have poor predictive validity and yield relatively high prevalence rates (Maciejewski et al., 2016). The current study was primarily concerned with comparing the DSM-5 criteria for PCBD and ICD-11 criteria for PGD, because these criteria are now included in the two internationally most frequently used systems for psychiatric classification and because, apart from Boelen et al.'s (2018) study, no prior studies have compared the performance of these criteria.

2. Methods

2.1. Participants and procedure

Data were available from 551 bereaved individuals who participated in two consecutive research projects on characteristics and correlates of disturbed grief. In both projects, participants were recruited via announcements on internet websites. After completing an application form, they were sent paper questionnaires or referred to a secured internet website to complete questionnaires online. In the first project, 568 individuals applied for participation, and 404 (71%) completed questionnaires; in the second project, 586 people applied and 409 (69.8%) participated. Informed consent was obtained from all participants. In the present study, we used data from all participants aged > 17 years, whose losses had occurred at least 6 months and maximally 20 years ago; yielding 259 participants from the first and 292 from the second project and, in total, $N = 551$ for the current analyses. Participants not included were mostly bereaved less than 6 months earlier. The mean age of the participants was 41.8 ($SD = 12.5$) years. Most ($n = 501$, 90.9%) were women. Highest education was college/university for 301 (54.6%) participants and lower than that for the other 246 (44.6%) participants; 173 (31.4%) had lost a spouse, 105 (19.1%) a child, and 273 (49.5%) someone else. Losses occurred $M = 42.4$ ($SD = 46.2$) months earlier, and were due to a nonviolent/natural cause in 453 (82.2%) and a violent/unnatural cause in 95 (17.2%) participants.

2.2. Measures

Items representing DSM-5 PCBD and ICD-11 PGD symptoms were obtained from the 29-item Dutch version of the Inventory of Complicated Grief-Revised (ICG-R; Boelen et al., 2003) and 15-item depression subscale¹ from the Symptom-Checklist-90 (SCL-depression; Arrindell and Ettema, 2003). The ICG-R taps different markers of disturbed grief and instructs people to rate their occurrence during the previous month on 5-point scales (1 = never, 5 = always). The SCL-depression scale measures the severity of depression symptoms during the previous week on 5 point-scales (1 = not at all, 5 = extremely). All 16 DSM-5 PCBD-symptoms except "Difficulty positive reminiscing about the deceased" were represented by 12 ICG-R and 3 SCL-depression items; all 12 ICD-11 PGD-symptoms were represented by 9 ICG-R and 3 SCL-depression items (Table 1). A symptom was considered

"absent" when rated with a 1, 2, or 3 response and "present" when rated with 4 or 5 (on its 5-point scale).

2.3. Statistical analyses

Confirmatory factor analysis in Mplus (version 8.0, Muthén and Muthén, 1998–2017) was used to evaluate the dimensionality of DSM-5 PCBD-criteria and ICD-11 PGD-criteria. For PCBD, we successively evaluated a one-factor model, a two-factor model with correlated clusters of separation distress (factor 1) and reactive distress and social/identity disruption (factor 2), and a three-factor model with correlated factors of separation distress (factor 1), reactive distress (factor 2), and social/identity disruption (factor 3), respectively. For ICD-11 PGD, we evaluated a one-factor model and two-factor model with correlated clusters of separation distress and accompanying symptoms. Because the number of observations for some response categories (e.g., 8 out of 15 PCBD items) were low (i.e., $\leq 5\%$), we dichotomized responses categories such that categories 1, 2, and 3 were recoded as 0, and categories 4 and 5 were recoded as 1.

A weighted least square mean and variance adjusted (WLSMV) estimator was used. Goodness of fit was evaluated using the Comparative Fit Index (CFI), the Tucker-Lewis index (TLI; values > 0.90 indicating good fit), and the root mean square error of approximation (RMSEA; values < 0.08 indicating acceptable fit). Lastly, the DIFFTEST command was used to compare the statistical fit between the different PCBD (1-factor vs. 2-factor vs. 3-factor model) models and PGD (1-factor vs. 2-factor) models.

Then, numbers of DSM-5 PCBD-cases and ICD-11 PGD-cases were counted. Criteria for probable DSM-5 PCBD-caseness required the endorsement of ≥ 1 separation distress symptom (symptoms 1–4, Table 1), ≥ 6 symptoms of reactive distress and social/identity disruption (symptoms 5–16, Table 1), and the ICG-R functional impairment item ("I believe that my grief has resulted in significant impairments in my social, occupational, or other areas of functioning"). Criteria for probable ICD-11 PGD-caseness required the endorsement of ≥ 1 separation distress symptom (symptoms 1–2, Table 1), ≥ 1 accompanying symptom (symptoms 3–12, Table 1), and the functional impairment item (WHO, 2018, see also Mauro et al., 2018).² Pairwise agreement between tests was evaluated using kappa statistics. Chi square tests and *t*-tests were used to compare cases and non-cases of DSM-5 PCBD and ICD-11 PGD in terms of sociodemographic and loss-related characteristics. Finally, we calculated rates of ICD-11 PGD, and evaluated the diagnostic agreement between DSM-5 PCBD and ICD-11 PGD criteria sets, when increasing the number of accompanying symptoms required for a diagnosis of ICD-11 PGD.

3. Results

3.1. Confirmatory factor analyses

Fit-indices for DSM-5 PCBD were: CFI = 0.974, TLI = 0.970, and RMSEA = 0.047 for the one-factor model; CFI = 0.974, TLI = 0.969, and RMSEA = 0.048 for the two-factor model; and CFI = 0.977, TLI = 0.973, RMSEA = 0.045 for the three-factor model. Thus, the three-factor model showed the best fit to the data, which was also evidenced by a significant Chi square difference test between the one- and three-factor model ($\Delta\chi^2 = 17.14$ (3), $p < .01$) and two- and three-factor model ($\Delta\chi^2 = 14.96$ (2), $p < .01$). Correlations between factors were 0.97 for separation distress with reactive distress, 0.94 for separation distress with social/identity confusion, and 0.88 for reactive

¹ Originally, the scale includes 16 items but 1 item referring to sexual interests was not included in the current studies.

² The timing criterion was ≥ 6 months for both the DSM-5 PCBD and ICD-11 PGD criteria sets, because an evaluation of differences and overlap between the symptom criteria was deemed more important than a comparison based on differences in the timing criterion.

Table 1
Symptoms of DSM-5 PCBD and ICD-11 PGD, symptom matching with the ICG-R and SCL-depression scale, factor-loadings, and percentage of participants with symptoms present.

Persistent Complex Bereavement Disorder	Item match	Factor loadings (Three-factor model)	% with symptom present	Symptoms of Prolonged Grief Disorder	Item match	Factor loadings (One-factor model)	% with symptom present
1 Persistent yearning/longing for the deceased	I feel myself longing and yearning for [...]	.76	58.8	1 Longing for the deceased	1 I feel myself longing and yearning for [...]	.74	58.5
2 Intense sorrow and emotional pain	Crying easily*	.62	25.8	2 Persistent preoccupation with the deceased	2 I think about [...] so much that it can be hard to do the things I normally do	.82	15.2
3 Preoccupation with the deceased person	I think about [...] so much that it can be hard to do the things I normally do	.85	15.2	3 Accompanied by: Intense emotional pain, e.g.:	3 Crying easily*	.64	25.8
4 Preoccupation with circumstances of the death	Memories of [...] upset me	.75	19.8	Sadness			
5 Difficulty accepting the death	I feel that I have trouble accepting the death	.80	24.3	4 Guilt	4 I feel that it is unfair that I should live when [...] died.	.72	13.6
6 Disbelief or numbness	I feel like I have become numb since the death of [...]	.85	16.5	5 Anger	5 I can't help feeling angry about [...]’s death	.62	25.8
7 Difficulty positive reminiscing about deceased	- not assessed -	-	-	6 Denial	6 I go out of my way to avoid reminders that [...] is gone	.36	2.7
8 Bitterness or anger	I can't help feeling angry about [...]’s death	.64	25.8	7 Blame	7 Blaming yourself for things*	.56	12.9
9 Maladaptive appraisals about the self associated with the loss (e.g., self-blame)	Blaming yourself for things*	.57	12.9	8 Difficulty accepting the death	8 I feel that I have trouble accepting the death	.80	24.3
10 Excessive avoidance of stimuli	I go out of my way to avoid reminders that [...] is gone	.43	2.7	9 Feeling one has lost a part of one's self	9 I feel that a part of me died along with the deceased	.79	41.7
11 A desire to die to be with the deceased	Thoughts of ending your life*	.80	2.9	10 An inability to experience positive mood	10 Feeling no interest in things*	.77	12.7
12 Difficulty trusting other people	Ever since [...] died it is hard for me to trust people	.64	17.6	11 Emotional numbness	11 I feel like I have become numb since the death of [...]	.79	16.5
13 Feeling alone or detached from other persons	I feel lonely ever since [...] died	.84	38.1	12 Difficulty in engaging with social or other activities	12 I feel like the future holds no meaning or purpose without [...]	.81	16.2
14 Feeling that life is empty or meaningless or one is unable to function without the deceased	I feel that life is empty or meaningless without [...]	.90	24.7				
15 Confusion about one's role and diminished identity (e.g., feeling that part of self died)	I feel that a part of me died along with the deceased	.80	41.7				
16 Difficulties to pursue interests or plan for the future (e.g., friendships, activities)	I feel like the future holds no meaning or purpose without [...]	.88	16.2				

Note. All items are from the Inventory of Complicated Grief-Revised (ICG-R), except those marked with

* which are taken from the Symptom Checklist SCL-depression subscale. PCBD = Persistent complex bereavement disorder; PGD = Prolonged grief disorder.

distress with social/identity confusion. Fit indices for ICD-11 PGD were: CFI = 0.977, TLI = 0.972, and RMSEA = 0.044 for the one-factor model; and CFI = 0.976, TLI = 0.971, and RMSEA = 0.045 for the two-factor model. The correlation between factors in the latter model was 0.98 and the two-factor model did not show a significantly better fit than the one-factor model ($\Delta\chi^2 = 0.14$ (1), $p = .71$). Thus the one-factor model was retained. Table 1 shows factor loadings of the three-factor model for DSM-5 PCBD and the one-factor model for ICD-11 PGD.

3.2. Diagnostic rates and agreement

The probable diagnostic rate for DSM-5 PCBD was 8.2% ($n = 45$) and for ICD-11 PGD it was 19.2% ($n = 106$). Table 1 shows mean scores for each item and percentages of participants with symptoms “present”. The difference in diagnostic rates according to the two criteria sets was statistically significant (Fisher's exact test, $p < .001$). There were 2 (0.4%) ‘unique’ PCBD-cases (meeting PCBD-criteria but not PGD-criteria). There were 63 (11.4%) ‘unique’ PGD-cases (meeting PGD-criteria but not PCBD-caseness). Forty-three (7.8%) participants met criteria for both PCBD and PGD; yielding a Kappa of 0.51 ($SE = 0.05$, $p < .001$).

3.3. Concurrent validity

Compared to participants not meeting DSM-5 PCBD-criteria, participants meeting PCBD-criteria had significantly higher ICG-R total-scores ($M = 113.0$, $SD = 9.8$ vs. $M = 67.7$, $SD = 20.4$, $t = 26.26$) and SCL-depression total-scores ($M = 56.7$, $SD = 11.6$ vs. $M = 31.7$, $SD = 12.2$, $t = 13.15$). Likewise, compared to participants not meeting ICD-11 PGD-criteria, participants meeting PGD-criteria had higher ICG-R total-scores ($M = 97.9$, $SD = 16.3$ vs. $M = 65.1$, $SD = 20.1$, $t = 17.76$) and SCL-depression total-scores ($M = 46.9$, $SD = 13.9$ vs. $M = 30.6$, $SD = 12.0$, $t = 12.15$; all p 's $< .001$).

3.4. Sociodemographic correlates of DSM-5 PCBD-caseness and ICD-11 PGD-caseness

We examined whether DSM-5 PCBD-cases and non-cases differed in terms of the socio-demographic and loss-related variables that we assessed, i.e., age, gender, dichotomized education, kinship to the deceased, time since loss, and dichotomized cause of death. Compared to non-cases, participants with probable PCBD had lower education ($\chi^2 = 9.32$, $p < .001$). In addition, those with probable PCBD were bereaved more recently ($M = 24.5$, $SD = 21.6$ vs. $M = 44.0$, $SD = 47.5$ months, $t = -5.06$, $p < .001$). There was a trend toward more PCBD-cases following unnatural vs. natural loss ($\chi^2 = 2.97$, $p = .099$). PCBD-cases and non-cases did not differ significantly in terms of gender, age, and relationship to the deceased (all p 's > 0.40).

Similar analyses were conducted comparing ICD-11 PGD-cases and non-cases. Compared to non-cases, participants with probable PGD had lower education ($\chi^2 = 12.60$, $p < .001$) and were bereaved more recently ($M = 25.5$, $SD = 29.1$ vs. $M = 46.4$, $SD = 48.5$ months, $t = -5.73$, $p < .001$). PGD-cases and non-cases did not differ significantly in terms of gender, age, cause of death, and relationship to the deceased (all p 's $> .19$).

3.5. Diagnostic rates and agreement with heightened thresholds for ICD-11 PGD-caseness

Heightening the threshold for the required number of accompanying symptoms for ICD-11 PGD-caseness yielded a reduction in prevalence rates and an increase in agreement with DSM-5 PCBD-caseness. That is, with two accompanying symptoms, PGD-prevalence = 17.6%, Kappa = 0.56; with three accompanying symptoms, PGD-prevalence = 15.4%, Kappa = 0.62; with four accompanying symptoms, PGD-prevalence = 11.1%, Kappa = 0.75; with five

accompanying symptoms, PGD-prevalence = 8.3%, Kappa = 0.84; and with six accompanying symptoms, PGD-prevalence = 5.3%, Kappa = 0.71.

4. Discussion

This study sought to expand knowledge on the differences and overlap of criteria for PCBD (DSM-5) and PGD (ICD-11). A first main finding was that confirmatory factor analyses supported the DSM-5 model of PCBD distinguishing clusters of separation distress, reactive distress, and social/identity disruption. One prior study (Boelen et al., 2018) also supported the three-factor PCBD model. The current findings substantiate that it may be useful for future research and clinical work to focus on maintaining mechanisms of these three clusters. Our analyses did not support a two-factor model of ICD-11 PGD symptoms, but, instead, suggested that these formed a single dimension of disturbed grief. One reason that ICD-11 PGD symptoms were best represented by one factor may be that the grief response equally caused separation distress and accompanying emotional pain symptoms. However, this particular finding contrasted with the aforementioned study (Boelen et al., 2018), suggesting that the dimensionality of the ICD-11 PGD criteria warrants further scrutiny.

A second main finding was that diagnostic rates for PCBD were substantially lower than for ICD-11 PGD, representing only a moderate agreement (Landis and Koch, 1977); this adds to prior work yielding similar suboptimal agreement (Boelen et al., 2018). This finding is concerning given that both conditions of disturbed grief ideally would identify the same groups of people. Our findings that ICD-11 PGD symptoms formed a unitary factor in our data-set did not impact low prevalence rates for ICD-11 PGD, because these rates were calculated based on the ICD-11 algorithm (requiring endorsement of ≥ 1 separation distress symptom, ≥ 1 accompanying symptom, and the functional impairment item; Mauro et al., 2018). As anticipated, ICD-11 PGD-rates went down and agreement with DSM-5 PCBD went up when we heightened the ≥ 1 symptom-threshold for accompanying symptoms for ICD-11 PGD. Accordingly, as also noted by other researchers (Mauro et al., 2018), heightening this threshold may be one way to consider, when looking for ways to harmonize the definitions of disturbed grief in DSM-5 and ICD-11. Attesting to the concurrent validity of DSM-5 PCBD and ICD-11 PGD-sets, participants meeting criteria for probable PCBD-caseness evidenced higher levels of overall disturbed grief and depression compared to non-cases. Similarly, ICD-11 PGD-cases had more severe overall disturbed grief and depression than non-cases.

DSM-5 PCBD-rates and ICD-11 PGD-rates were found to vary as a function of education and time since loss. At a trend-level ($p < .10$), PCBD-rates were higher following unnatural/violent losses vs. natural/nonviolent loss. These subgroup differences are largely consistent with prior work on risk factors of disturbed grief. For example, there are prior studies that have shown that higher education is a protective factor limiting the emotional impact of bereavement (Lobb et al., 2010). Higher education possibly fosters cognitive processing of the loss or may promote recovery from loss through its association with social resources. Prior work has also pointed that more severe levels of disturbed grief are observed in the earlier months of bereavement (e.g., Lenferink et al., in press), although associations are generally not strong, indicating that time heals, but only for a minority of bereaved individuals with initially high levels of grief.

The current study has several limitations. First, symptoms were assessed using self-report measures and obtained from two different questionnaires. Future work should preferably use clinical interview-based assessment of symptoms. Secondly, women were overrepresented and this may limit generalizability of the current findings. Third, the absence of longitudinal measures precluded assessment of predictive validity of DSM-5 PCBD and ICD-11 PGD, which is critical to the evaluation of the diagnostic utility of these conditions.

Notwithstanding these limitations, our findings offer useful

information suggesting that the overlap of disturbed grief as per DSM-5 and ICD-11 is moderate. This may be problematic for research (as it limits the generalization of findings based on one criteria set to the other criteria set) and clinical practice (where different people may be identified for treatment dependent on what criteria set is used). It is important to find ways to harmonize disturbed grief in the diagnostic systems of the DSM and ICD; heightening the number of symptoms required for a diagnosis of PGD as per ICD may be one such way, including criteria for prolonged grief disorder as proposed by Prigerson et al. (2009)—which have proven to form a diagnostic entity that is very similar to DSM-5's PCBD (Maciejewski et al., 2016)—would be another way.

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