Context

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In March 2010, we presented our proposal for Prolonged Grief Disorder (PGD) to the DSM-5 Anxiety, Obsessive-Compulsive Spectrum, Posttraumatic, and Dissociative Disorders Work Group (hereafter, "DSM Work Group"). At that meeting, we provided substantial, peer-reviewed, empirical evidence that PGD meets criteria for a new diagnostic category, based not only on our own investigations, but also on those of grief researchers worldwide. This discussion included Dr. Shear and members of the DSM Work Group. At that time, neither Dr. Shear nor DSM Work Group members presented any proposal for a disorder of grief.

Since that initial collective meeting, Dr. Shear and her colleagues have proposed two different, perhaps irreconcilable, proposals for a disorder they call Complicated Grief (CG). (2, 3) Subsequently, the DSM Work Group has proposed criteria for a disorder they call Persistent Complex Bereavement-Related Disorder (PCBRD). Neither Shear and her colleagues, nor the DSM Work Group, have presented any peer-reviewed, empirical evidence that CG or PCBRD, respectively, meets criteria for a new diagnostic entity.

Our original proposal for PGD (1) is the only credible proposal for the inclusion of a disorder of grief in DSM-5, yet these other proposals are presented and considered as if they are on equal evidentiary footing. Below we make our recommendations and critique of the proposals put forth.

Recommendations

Recommendation 1: Include PGD in DSM-5

Option #1: Include PGD as a new diagnostic category in DSM-5. Rationale: We have provided substantial evidence that PGD meets criteria for a new diagnostic entity. (1)

Option #2: Include PGD for further study as an appendix to DSM-5. Rationale: Specific gaps in evidence in support of PGD as a new diagnostic entity should be addressed in future research.

Recommendation 2: Do not include either CG or PCBRD in DSM-5

Rationale: There is no evidence that either of these constructs meets criteria for a new diagnostic category.

Terminology

Disorders of or related to grief have had various names in the research literature, e.g., "complicated," "traumatic," "pathological," and "prolonged" grief. We acknowledge that we have used many of these terms ourselves at one time or another, but have concluded that the best term for the new diagnostic category we propose is Prolonged Grief Disorder (PGD). This term provides the most accurate description of the essence of the syndrome, as others have also acknowledged (4).

The term "complicated" grief is perhaps best understood in relation to the term "uncomplicated bereavement," meaning bereavement without the "complication" of Major Depressive Disorder. (5) For Shear and her colleagues, CG is not a disorder of grief. It is grief "complicated" by the presence of psychiatric disorders and symptoms. This point has been made clear by one of this group's prominent members, Dr. Zisook. In response to the question "when should grief be considered a mental illness?," Dr. Zisook replies simply "never." (6) We note that a normal response to loss (grief) accompanied by existing mental disorders does not constitute a new

mental disorder.

Prior to the DSM Work Group's proposal for PCBRD, the term "persistent complex bereavement-related disorder" had not been used in the research literature. This term appears an attempt to merge the terms "prolonged" grief and "complicated" grief without using the words "prolonged," "complicated," or "grief," as if these terms adopted by researchers in the field of grief and bereavement do not matter. The DSM-5 decision here appears to be politically motivated, driven by fears of public backlash, rather than a thoughtful decision to use precise terminology (e.g., they appear reluctant to use the term "grief" because of a fear of public outrage that they are pathologizing normal grief).

The Case for Prolonged Grief Disorder (PGD)
In 2009, we made our case for the inclusion of PGD in DSM-5 in the open scientific literature. (1) We will not repeat ourselves here as our PLoS Medicine publication provides the arguments and data. What that report does not provide is evidence from a vast number of international investigations that have validated these criteria in other cultures, circumstances of the death, age of the survivor and deceased as well as kinship relationships. (We are eager to send those interested a map and list of studies that have done this upon request.) Ours is the only proposal that meets criteria for mental disorder as outlined in Stein et al. (7).

Reply to Shear et al.'s (3) criticism of PGD
For science to progress, investigators need to build upon what is known and address limitations of prior studies. The main question is, "to what extent does the study advance the field?" Our criteria for PGD (1) build on prior work of a consensus conference on diagnosing dysfunctional grief, (8) attempt to unify the field, and move the work forward. Shear et al.'s (3) criteria for CG disregard the substantial evidence base for PGD criteria, appear to start from scratch, and do not address the relevant limitations, thereby, setting the field backwards.

We address Shear et al.'s (3) criticisms of our criteria for PGD (in quotes below) point by point. We are eager for others to evaluate the merits of these criticisms.

"Yearning is proposed as a necessary symptom (Criterion B) but it is not clear how and why this decision was made."
In our paper, (1) we clearly state "Based on consensus opinion of the previously mentioned expert panel, and confirmed by results showing yearning was the most common (68.3%) and most informative (Imax = 0.94) of the 12 items… yearning was specified as a mandatory symptom." We note that Drs. Shear, Zisook, and Reynolds were members of this consensus panel, as well as authors on the paper we cite on this point, (8) which includes yearning as the primary exemplar of the expert panel's proposed mandatory criterion of intrusive preoccupation with the deceased person (Table 1, Criterion A). To our statement in PLoS Medicine, we would now add that yearning is the sole symptom to date that is both specific to grief and found to be directly related to specific brain circuitry, i.e., through reward-related activity in the nucleus accumbens. (9) Therefore, yearning as an essential element of grief is supported by expert opinion, (8) rigorous psychometric analysis, (1) and present understanding of the neurobiology of grief. (9)

"The sample from which these criteria were derived is not a clinical one..."
This criticism displays a lack of understanding that diagnostic criteria for a grief disorder must first and foremost distinguish pathological grief from normal grief. That our criteria for PGD allow us to distinguish PGD from normal grief in a community sample is a strength of our approach, not a weakness.

"Therefore, it is only partially informative for deriving clinically useful criteria."
This criticism confuses the issue of diagnostic efficiency with that of clinical utility. Our criteria for PGD are remarkably diagnostically efficient in that they allow us to identify reliably and accurately individuals with PGD (e.g., sensitivity = 1.0; specificity = .99). Clinical utility, not addressed specifically in our PLoS Medicine paper, would include considerations such as how the criteria facilitate communication about the clinical management of the disorder. We have an NIMH proposal (for which funding is pending) to evaluate the clinical utility of PGD, collaborating with Michael First and applying his operationalization of clinical utility (10).

On the point of clinical utility, we observe that several of Shear et al.'s (3) criteria for CG would be difficult to apply. For example, how is a clinician supposed to determine whether a person's symptoms have been "present for a period longer than is expected by others in the person's social or cultural environment"? That is, Shear et al. (3) propose that symptoms of one person are to be determined by the states of mind of others – a clinical challenge, to say the least.

"The sample… was relatively small (n=291)…"
This is a vacuous criticism in that it does not relate the purported limitation (here sample size) to the reliability or validity of our results. The implication is that this sample size somehow invalidates the findings without any specifics provided about why the sample size of 291 is insufficient for our purposes.

"The sample… included almost exclusively older (average age 62) white (95%) widows (84%), with 60% educated beyond high school…"
According to the 2000 US census, 73.3% of all deaths in the US in 1995 occurred at age 65 and older. It almost goes without saying that death and bereavement disproportionately affect the elderly, particularly widows. If there were any age group for which diagnostic criteria for PGD need to be applicable, older adults would be this group.

In our differential item functioning analysis of symptoms of grief, (1) we examined whether measurement characteristics of ICG symptoms differed with respect to age, gender, education, relationship to the deceased, and time from loss. Through these analyses we were able to identify and eliminate from further consideration symptoms that were biased with respect to these characteristics. We note that Shear et al. (3) include a symptom (loneliness) in their criteria for CG which we found to be biased with respect to gender, relationship to the deceased, and time from loss.

"Data used were from study subjects bereaved from 0 to 6 or from 6 to 12 months, yet the authors propose that PGD should not be diagnosed before 6 months… It is questionable whether CG criteria should be derived using data from individuals considered ineligible for the diagnosis."
The question of timing for a diagnosis of PGD is critical. Our examination of individuals over a wide range of time post-loss allows us to draw boundaries between normal grief reactions and PGD. Again, diagnostic criteria need to differentiate between normal and pathological conditions.

"…the ICG-R does not include several symptoms that have been associated with CG and that should be considered as possible criteria, e.g. rumination, physical reactions to the death, and suicidality."
Shear and her colleagues feel compelled to add to our set of extremely well performing criteria for PGD (recall, sensitivity = 1.0; specificity =.99 in the PLoS Medicine analysis). The additions

they propose detract from the precision of our criteria. Rumination is a known symptom of depression, “physical reactions” is non-specific and could mean almost anything, and suicidality is an outcome in its own right.

“IRT modeling…its validity is based on an initial assumption that the attribute being measured is best represented as a single factor.”
The implicit criticism here is that our analysis of symptoms for PGD is based on an assumption (the unidimensionality of our underlying grief attribute) that may not be valid. As we state in our PLoS Medicine paper, (1) the grief attribute that forms the basis of our IRT evaluation of symptoms of grief is unidimensional according to Cattell’s scree test. Many others, including Simon et al. (11) on whom Shear bases her diagnostic formulation, have also found grief as measured by ICG items to be unidimensional. (12)

“…unidimensionality is usual in a group of people with a wide range of scores on an attribute…”
This statement is a testament to the ignorance of this group when it comes to measurement theory. One would think that understanding basic concepts of measurement theory would be a core competency, or pre-requisite, for those proposing diagnostic criteria. Neither Shear et al. nor the DSM-5 Workgroup appears to be comprised of members who are familiar with basic concepts of measurement theory. This state of affairs is unfortunate. The ill-informed comments of psychiatrists such as Shear et al., which reveal deficiencies in a basic understanding of psychometric principles, are apparently taken quite seriously by the DSM Workgroup. Suffice it to say, there is no logical connection between a range of scores and the dimensionality of an underlying construct.

The Case for Complicated Grief (CG)
Recently, Shear and her colleagues of have made two proposals for inclusion of CG in DSM-5. (2, 3) Their first proposal (2) is not cited by them in the formulation of their second proposal. (3) Because Shear and her colleagues do not take their own initial proposal for CG seriously, neither will we. Therefore, we focus our attention on their second proposal. At the outset, we observe that there is no evidence in support of CG as a new diagnostic category as outlined in Stein et al. (7) There is neither evidence CG is fundamentally a disorder of grief, nor evidence CG is distinct from other mental disorders. CG should not be included in DSM-5 for these reasons alone.

Critique of Shear et al.’s (3) proposal for CG
Shear et al. (3) contend that symptoms of CG are those that best characterize clinically “confirmed” cases of CG, in contrast to clinical non-cases of CG.
Among the “confirmed” cases of CG reported in Simon et al., 73% met criteria for an existing diagnostic category. Furthermore, according to Shear et al., (3) at least 11.5% of their “confirmed” cases of CG would not have met criteria for PGD. Therefore, the vast majority of Simon et al.’s (11) “confirmed” cases of CG met criteria for other mental disorders, and some did not meet criteria for the only proposed mental disorder that is specific to grief. Thus, as Shear et al. (3) define it, CG is a highly co-morbid condition that is not necessarily specific to grief. Rather, it is conceived as any of several psychiatric “complications” of bereavement (e.g., MDD, PTSD, GAD).

The diagnostic “nearest neighbors” of any would-be disorder of grief are MDD, PTSD, and GAD. Among “confirmed” cases of CG in Simon et al., (10) 51%, 34%, and 21% met diagnostic criteria for MDD, PTSD, and GAD, respectively. Among their non-cases of CG, only 13%, 5%, and 8% met criteria for MDD, PTSD and GAD, respectively. Thus, in the construction of their CG and non-CG groups for their analysis, (10) Shear and her colleagues confound CG with its

diagnostic “nearest neighbors.” Their analysis (10) and proposed criteria for CG (3) demonstrate that they are able to differentiate some bereaved individuals who are more likely to meet criteria for MDD, PTSD, and GAD from other bereaved individuals who are less likely to meet criteria for those disorders. This exercise is at best irrelevant, and more likely antithetical, to the case that CG ought to be advanced as a new diagnostic category.

The Case for Persistent Complex Bereavement-Related Disorder (PCBRD)
No case has been made for the inclusion of PCBRD in DSM-5. There is no evidence in support of it as a new diagnostic category. For these reasons, PCBRD should not be included in DSM-5.

Closing Remarks
Bereavement research and clinical care has made giant strides forward in the past few decades. A research base has been built that has used a uniform and agreed upon (i.e., standardized) metric for evaluating and diagnosing dysfunctional grief. The evidence to date provides a wide and solid foundation on which to build and move the field forward.

It is our view, and that of others (4), that the DSM-5 Workgroup did not critically evaluate the evidence made available to it. We believe that building from what we have learned from PGD is the scientifically sound approach. To dismiss what has been learned about PGD in favor of de novo, untested PCBRD criteria that muddy its clarity by combining it with untested Shear et al. criteria, is to create needless confusion. This move will do substantially more harm than good to bereavement research and clinical care. The proposed inclusion of PCBRD jeopardizes the gains made to date in the field of bereavement and will set the field of bereavement back decades.

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