Prolonged Grief Disorder (PGD)

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This paper will investigate and detail various aspects of one of the most recent DSMV-TR diagnostic additions known as *prolonged grief disorder (PGD).* I am interested in investigating this disorder due to the culture of relative acceptance that has developed around grief and bereavement in recent years throughout the West. Although removing stigma from a topic previously (and presently still) regarded as "taboo" has created a somewhat revolutionary shift—regardless of the fact that grief, loss and death are among some of the few constants we can count on as human beings—I think that a distinction between "healthy" grief and "harmful" grief can be useful to those who suffer "abnormally", especially when functional consequences that increase the risk for physical disease are at play. I will also touch upon how the comorbidity of this diagnosis with substance use disorders has presented a fascinating and budding field of research within the study of grief addiction as well as present a brief musing upon the controversy surrounding associated features of this diagnosis including hallucinations and interactions with the deceased.

Throughout, the questions that will be explored include: What is "normal" grieving and when does it become "pathological"? Who is at risk of developing PGD and what are the risks of living with it untreated? Is grief addiction real? Are interactions with the dead pathological, spiritual or both? Can they become valuable as or part of a course of treatment for the disorder itself? Which roles do the arts play in the process?

Before diving in, it feels pertinent to re-acknowledge to some degree of depth that grief exists amongst the most natural and normal elements of human (and other mammalian) experience. The conversation about when such grief becomes "abnormal" then presents a potentially preliminary step towards a re-alignment with the self and our nature as human beings

who love and lose. If we remember to break down the term psycho(soul)-path(suffering)-ology(the study of) into its Greek antecessors, we re-orient ourselves back to the heart of our roles as helping professionals who are concerned with the suffering of our collective and individual souls as a species. In this way, recovery from any condition, including excessive or otherwise "abnormal" grief, is made simultaneously in service of re-integration with others and our Earth at large, which is where an initial diagnosis can become useful or necessary.

Prolonged grief disorder (PGD) is one among numerous additions/changes made in the most recent revision of the Diagnostic and Statistical Manual of Mental Disorders Fifth Addition Text Revision (DSMV-TR), marking its transition from its diagnostic cousin known as prolonged complex bereavement disorder (PCBD) as previously proposed for inclusion in the DSMV. Since the official induction of PGD as a DSMV-TR diagnostic category occurred only one year ago, I will supplement, cross-reference and attempt to compare/contrast between it and the research and information available about PCBD due to its own decade's long presence within the DSM as well as the collective consciousness of the field when appropriate and necessary. Additionally, there are several distinctions made between criteria for and manifestations of PGD in children and adolescents versus adults throughout its section in the DSMV-TR; For the purposes of this paper, I will be focusing upon the adult experience of PGD.

Listed under the diagnostic category of trauma and stressor-related disorders in the DSMV-TR, PGD is loosely defined as "a persistent pervasive grief response that continues to cause clinically significant distress or impairment for more than 12 months after the death of someone close" (DSMV-TR; American Psychiatric Association, 2022, Differential Diagnosis subsection in Major Depressive Disorder section). In contrast, Robinaugh et.al. (2014) describe persistent complex bereavement disorder (PCBD) as "a bereavement-specific syndrome

characterized by prolonged and impairing grief" (para.1). Though the above definition of PCBD is clearly less specific, it is unclear exactly what is the difference between these two conditions and why the American Psychiatric Association changed the terms from PCBD to PGD. Further confounding is that each share much of the same content within their diagnostic criteria. For example, PGD's diagnostic criteria include the following: the death of a person close to the bereaved individual *at least* 12 months ago; most days since the death and nearly every day for at least the previous month to a clinically significant degree, the bereaved individual experiences either an intense yearning or longing for the deceased person and/or preoccupation with thoughts or memories of the deceased are present; at least three of the following symptoms have been present most days since the death and nearly every day for at least the previous month: identity disruption/feeling that part of oneself has died in conjunct with the deceased person's own death; disbelief about the death itself (denial); avoidance of reminders that the person is in fact dead (more denial); intense emotional pain related to the death (i.e. anger, bitterness, sorrow); difficulty with eventual reintegration into other relationships, activities and obligations following the death; emotional numbness as marked by an absence of or reduced emotional experience as a result of the death; feeling that life is meaningless as a result of the death; and intense loneliness as a result of the death (DSMV-TR; American Psychiatric Association, 2022).

The DSMV (2013) lists most of the above as symptomologies of PCBD yet differs in that it also separates them into categories of "reactive distress to the death" and "social/identity disruption" and also requires at least eleven overall symptoms to be present in order to achieve a diagnosis versus the eight required by the DSMV-TR's PGD (DSM5; American Psychiatric Association, 2013, p.790 ; DSMV-TR; American Psychiatric Association, 2022). Symptoms which did not transfer over to PGD's establishment within the DSMV-TR from the DSMV's

PCBD include: difficulty with positive reminiscing about the deceased, difficulty trusting others since the death and most dramatically, a desire to die in order to be with the deceased (DSMV; American Psychiatric Association, 2013). It is also interesting to note that the DSMV listed maladaptive appraisals about oneself in relation to the deceased as an element of diagnostic criteria for PCBD whereas the DSMV-TR lists the experience of maladaptive cognitions about the self, guilt about the death and self-imposed diminished future life expectancy and life goals as an associated feature of PGD. Both conditions share the other fascinating associated features of somatic complaints resulting in increased health care visits; somatic symptoms that may have been experienced by the deceased prior to and/or related to their death (hello mirror neurons!?); hallucinations about/interactions with the deceased especially amongst those with marked disrupted perception of self and purpose (DSMV; American Psychiatric Association, 2013; DSMV-TR; American Psychiatric Association, 2022).

Likewise interesting is that PCBD possessed a purported 2.4%-4.8% prevalence rate with higher prevalence in females than males in the DSMV (2013) whereas PGD poses a 9.8% prevalence rate with no definitively conclusive or otherwise statistically significant variation of occurrence amongst the genders according to the DSMV-TR (2022). The DSMV-TR goes on to denote that populations with higher trauma exposure are more likely to have higher prevalence rates of PGD and that the mean prevalence of PGD symptomology may be more elevated in high-income Western countries than in high- and upper-middle-income Asian countries—though these estimations continue to fluctuate. The data presented on development and course between both PGD and PCBD are similar, suggesting that usually symptoms begin throughout the first months following the death but there is some evidence which suggests there might be a delay before the complete manifestation of the disorder. The DSMV-TR further details that: the death

of a child may prolong the course of PGD among their surviving parents; comorbid PTSD (more common in cases of bereavement in response to a violent death such as homicide or suicide) further tends to complicate PGD's course especially when personal threat to the surviving individual's life is posed and/or if the individual witnessed the violent or otherwise gruesome death; and that older age, though not clearly defined, is suggested to be associated with higher risk of developing the disorder after the loss of a loved one in addition to putting older adults at higher risk for progressive cognitive decline (DSMV; American Psychiatric Association; DSMV-TR; American Psychiatric Association, 2022).

The functional consequences listed for both PGD and PCBD are almost identical, including: increased tobacco and alcohol use, marked increased risk for severe medical conditions such as cardiac disease, hypertension, cancer, immunological deficiency and overall reduction in quality of life. Additionally, the risk for developing either condition as listed in the corresponding literature is reported to be heightened by an increased dependency on the deceased prior to the death and by the death of a child. The DSMV-TR goes on to specify that violent or unexpected deaths and economic stressors further the risk of developing PGD, whereas the DSMV listed being female as a risk for developing PCBD. PGD also has greater prevalence along the heels of the death of a spouse/partner or child when compared with other kinship relationships to the deceased. Likewise, both sets of literature list heightened risk for suicidal ideation as a result of a PGD or PCGD diagnosis (DSMV-TR; American Psychiatric Association, 2022).

As with many psychological disorders, to be considered pathological, the above disturbances must cause clinically significant distress or impairment in social, occupational and/or other important areas of functioning as well as exceed expected social, cultural and/or

religious norms of the individual’s culture and context for both PGD and PCBD. Further, the symptoms must not be better explained by other potential differential diagnoses of PGD such as normal grief, depressive disorders, post-traumatic stress disorder (PTSD), separation anxiety disorder and psychotic disorder; differential diagnoses for PCBD’s included all but psychotic disorder. Both PGD and PCBD share the same comorbidities of major depressive disorder, PTSD and substance use disorder with the additional possibility of separation anxiety. Both the DSMV and the DSMV-TR also go on to acknowledge that various manifestations of disordered grief will vary upon an individual and cross-cultural basis; The DSMV-TR (2022) further outlines such affected areas including: duration of PGD, prevalence of nightmares, sleep quality, hallucinations, somatic grief experiencing, functional impairment, spirituality and social and economic status (DSMV; American Psychiatric Association; DSMV-TR; American Psychiatric Association, 2022).

Now that the basic similarities and differences between PGD and PCBD have been examined in detail, it becomes possible to examine various means of assessment and treatment of PGD as a DSMV-TR condition. Since PGD’s arrival on the market of diagnosable disorders, the diagnostic tool known as the PG-13-R has been revised and published using data obtained by the Yale Bereavement Study, Utrecht Bereavement Study and Oxford Grief Study (see appendix). The PG-13-R is a validated 13-item measurement tool designed to assess for symptoms of PGD by measuring client-reported symptoms upon a scale of intensity from not at all to overwhelming The meta-analysis presented across the three various studies suggests that the PG-13-R possesses desirable performance characteristics—inferring its applicability and efficacy in clinical use with clients (Prigerson et.al., 2021). While there exist a handful of other diagnostic grief assessments, such as the Inventory of Complicated Grief (ICG), it is apparently important to distinguish

"prolonged" grief from that which is considered "complicated" upon the basis that complicated grief is not included in the DSM5-TR and is therefore a type of grief that is not considered pathological. The semantic differences appear to be propagated by practitioners who refuse to accept grief in any form as pathological versus those who find its pathology useful or necessary, which poses another valid topic for an entirely different research paper (Maciejewski et.al., 2016).

Options for treatment, then, according to the American Psychiatric Association website include cognitive-behavioral therapy (CBT) and bereavement groups; ironically enough, a *complicated grief* treatment which combines elements of CBT and other efforts to help adapt to the loss is also cited in reference to possible treatment for PGD despite the aforementioned semantic rift within the field. Nonetheless, the beneficial elements of using CBT include working on acceptance of the loss and simultaneous potential for integration and recovery as well as goal-setting around attaining fulfillment in a world without the deceased person. Bereavement groups are cited to address the symptomology of PGD related to loneliness and isolation. Further, there are no current medications on the market to treat PGD or grief-specific symptoms.

Where the conventional options for treatment of grief specified as PGD appear limited, the expressive arts and several other mind-body informed practices offer more breadth and help. Dr. Elis Syuhaila binti Mokhtar offers a synergy of person-centered therapy (PCT) with visual journaling in the form of a "self-help toolkit" for those suffering with symptoms or a diagnosis of PGD or otherwise perpetuated bereavement symptoms vis a vis her fascinating 2019 autoethnobiographical doctoral thesis. Throughout, she details her grief experience in the wake of her decade-long separation from her son as a result of his tragic kidnapping by his own father, Mokhtar's ex-husband. Drawing upon two of PCT's core conditions of congruence to

"demonstrate genuineness by 'being honest' and 'being positive' to practice unconditional positive regard for herself and others became the foundation upon which Mokhtar led herself through a visual journaling practice wherein she drew daily images which focused on her on the spot feelings for a month (Mokhtar, 2019, p.ix). In addition to vulnerably providing anecdotal evidence of some of the key symptoms which mark PGD from normal grief such as Mokhtar's experience of a sense of meaningless, identity disruption and even suicidal ideation, what reportedly took place throughout her intuited self-healing process/autoethnographical research was a conversation with herself and an opportunity to put the unspeakable, unthinkable, unfathomable nature of her son's disappearance onto the page. In this way, Mokhtar, with cognitive assistance from principles of PCT, was able to work through much of her denial and otherwise stuck qualities that are so devastatingly characteristic of PGD via an implementation of the healing capacity of art-making (Mokhtar, 2019). In other words, she worked through her denial and other emotional states and experiences of her grief to arrive at what used to be the fifth and final step of Elizabeth Kübler-Ross's grief stages.

In recent years, Kübler-Ross's five stage theory has been revised by David Kessler with his addition of a sixth stage: finding meaning (Kessler, 2019). Likewise existentialist theory such as that presented in as Viktor Frankl's *Man's Search for Meaning* supports the immense value and necessity for human beings to find a reason to continue living in the face of atrocities as horrific as the holocaust as well as throughout both "big T" and "little t" traumatic losses as Dr. Gabor Matè refers to them in his book *The Myth of Normal: Trauma, Illness and Healing in a Toxic Culture*. The expressive arts are well adept and suited for this task as demonstrated throughout Barbara E. Thompson and Robert A. Niemeyer's work *Grief and the Expressive Arts: Practices for Creating Meaning*. The chapter specifically on the expressive arts in grief therapy

provides an in-depth qualitative and quantitative meta-analysis on the findings and benefits of music therapy which utilizes listening, song writing and playing, playing rhythmic instruments, writing therapy including poetry, journaling and narrative writing, horticultural therapy, performance art, painting and sculpture on several groups of variably bereaved patients, clients and helping professionals exposed to high amounts of loss. Most groups reported either significant improvement or at least significant reduction in bereavement and grief symptoms with an increase in coping and behavior scores upon re-assessment. I am most struck by the study which utilized elements of a secular remembrance ceremony in conjunction with music and poetic readings and am led to believe that one's spirituality or some sense of greater connection either with their loved one and/or a force greater than themselves can bolster the efficacy of whichever therapeutic intervention is employed (Torres et.al., 2014)

Wrapping up with this paper I am left with several remaining queries. To start, I am fascinated by PGD's common comorbidity of substance use disorders (DSM5-TR; American Psychiatric Association, 2022) and can't help but to wonder if cases of co-dependency upon or otherwise addictive emotional enmeshment with the deceased pre mortem adds yet another layer of comorbid complexity. While literature upon this exact topic is not yet available (and poses yet another interesting topic for future study), I did stumble upon a more recent addiction phenomenon known as *grief addiction* which seems a plausible "substance" specifier in the context of comorbidity with PGD.

According to a group of UCLA scientists, "long-term or "complicated" grief activates neurons in the reward centers of the brain" whereupon the memory of the deceased potentially possesses "addiction-like properties" (UCLA, 2008, para. 2); There exists the same neural reward that occurs in the living presence of our loved ones also after their deaths for those who

do not or perhaps cannot adapt to the loss. The continual craving of that reward becomes the addiction itself and the refusal, inability or otherwise denial which prevents a certain degree of acceptance about the fact of death therefore keeps the connection with the deceased alive. When such unconscious, yet drugstore-like nonetheless, behavior extends into that 12 month post mortem threshold we then see how the developing symptoms of PGD have the capacity to begin wreaking havoc on one's physical, interpersonal and material health as outlined above (UCLA, 2008).

However, as Dr. Karen Estrella suggests, perhaps the overall purpose of therapy is to ultimately learn how to say goodbye—inferring the sheer mass of this most gruesome task handed to us in the face of the inevitable loves and losses of our lives (Dr. Karen Estrella, group communication, 2023). The topic of hallucination and other general interaction with the deceased poses yet another interesting phenomenon which may simultaneously honor and address the humanity of the pathology of being unable able to let go when holding on begins to harm us, as in the case of PGD. What if there was a way to harness even these most "pathological" symptoms of the disorder as a means of treatment itself?

References

American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.)

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.)

Frankl, V. (1959). *Man's search for meaning.* Beacon Press.

Maciejewski, P.K., Maercker, A., Boelen, P.A., Prigerson, H.G. (2016). "Prolonged grief disorder" and "persistent complex bereavement disorder", but not "complicated grief", are one and the same diagnostic entity: an analysis of data from the Yale Bereavement Study. *World Psychiatry 15(3)*, 266-275. doi: 10.1002/wps.20348

Kessler, D. (2019). *Finding meaning: the sixth stage of grief.* Scribner.

Matè, G. (2022). *The Myth of Normal: Trauma, Illness and Healing in a Toxic Culture.* Avery.

Mokhtar, E. (2019). *The development of a self-help toolkit : a hybrid approach to PCT and visual journaling for prolonged grief disorder*.

Prigerson, H.G., Boelen, P.A., Xu, J., Smith, K.V., Maciejewski, P.K. (2021). Validation of the new DSM-5-TR criteria for prolonged grief disorder and the revised (PG-13-R) scale. *World Psychiatry 2021(20), 96-106.*

Prolonged grief disorder. Psychiatry.org - Prolonged Grief Disorder. (n.d.). Retrieved March 21, 2023, from https://www.psychiatry.org/patients-families/prolonged-grief-disorder

Robinaugh, D.J., LeBlanc, N.J., Vuletich, H.A., & McNally, R.J. (2014). Network analysis of persistent complex bereavement disorder in conjugally bereaved adults. *Journal of Abnormal Psychology, 123(3),* 510-522.

Torres, C., Neimeyer, R. A., & Neff, M. L. (2014). The expressive arts in grief therapy: An empirical perspective. In B. E. Thompson & R. A. Neimeyer (Eds.), Grief and the expressive arts: Practices for creating meaning (pp. 284–290). Routledge/Taylor & Francis Group.

University of California - Los Angeles. "Addicted To Grief? Chronic Grief Activates Pleasure Areas Of The Brain." ScienceDaily. ScienceDaily, 22 June 2008. <www.sciencedaily.com/releases/2008/06/080620195446.htm>.

Appendix

Prolonged Grief Disorder (PG-13-Revised)

Q1. Have you lost someone significant to you? ○ Yes ○ No

Q2. How many months has it been since your significant other died? ☐ Months

For each item below, please indicate how you currently feel

Since the death, or as a result of the death...	Not at all	Slightly	Somewhat	Quite a bit	Overwhelmingly
Q3. Do you feel yourself longing or yearning for the person who died?	○	○	○	○	○
Q4. Do you have trouble doing the things you normally do because you are thinking so much about the person who died?	○	○	○	○	○
Q5. Do you feel confused about your role in life or feel like you don't know who you are any more (i.e., feeling like that a part of you has died)?	○	○	○	○	○
Q6. Do you have trouble believing that the person who died is really gone?	○	○	○	○	○
Q7. Do you avoid reminders that the person who died is really gone?	○	○	○	○	○
Q8. Do you feel emotional pain (e.g., anger, bitterness, sorrow) related to the death?	○	○	○	○	○
Q9. Do you feel that you have trouble re-engaging in life (e.g., problems engaging with friends, pursuing interests, planning for the future)?	○	○	○	○	○
Q10. Do you feel emotionally numb or detached from others?	○	○	○	○	○
Q11. Do you feel that life is meaningless without the person who died?	○	○	○	○	○
Q12. Do you feel alone or lonely without the deceased?	○	○	○	○	○

Q13. Have the symptoms above caused significant impairment in social, occupational, or other important areas of functioning? ○ Yes ○ No