The psychopathological characteristics of prolonged grief

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Summary

Grief is a normal human response to the death of a loved one that may vary among individuals and in the way it manifests itself across cultures. Whereas the majority of bereaved people adjust adequately to the loss, a small but noteworthy proportion of individuals may experience a prolongation of the symptoms of acute grief well beyond the period when these have commonly abated. This syndrome, characterised by prolonged psychological distress in relation to bereavement, has been termed prolonged grief (PG) and shows distinct psychopathological features compared with other stress-related mental disorders. Accurately diagnosing PG in the context of difficult bereavement is an ongoing challenge to clinicians and researchers and many have called for improving the identification of PG and its treatment. PG has been recognised as a predictor of negative outcomes, such as substantial impairment in work and social functioning, reduction of quality of life, risk for mental disorders and suicidality, and physical health problems. This article discusses the main clinical features of PG, the determinants associated with the severity of PG symptoms, the risk factors that may predispose an individual to develop PG and the efficacy of different preventive and treatment approaches, including psychopharmacological and psychotherapeutic interventions.

Key words

Bereavement • Grief • Complicated grief • Traumatic grief • Prolonged grief disorder • Prolonged grief diagnostic criteria • Prolonged grief risk factors • Prolonged grief treatment

Introduction

Over the last 20 years, several studies have focused on complications of grief and bereavement. Assuming that bereavement is a normal human experience and that grief is the physiological reaction to the loss of a loved one, many researchers have attempted to identify the stages of grieving process as well as the order in which they may arise. Historically, Kübler Ross described grief as a succession of five steps according to a relatively linear “recovery” trajectory over time (the so-called five-stage model). Recently, it has been showed that bereaved people, in correlation with different individual and contextual features, may experience a range of symptoms during the whole process, and not necessarily in a sequential order. Empirical data have indeed supported the existence of distinct patterns of grieving, allowing recognition and study of different trajectories of the process. Evidence has demonstrated that most bereaved individuals finally succeed in coming to terms with the loss of their loved one and integrate this experience in their lives. The time period during which this process is completed has not been definitely established, but most experts agree that progress usually becomes apparent by 6 months. Even if possible intense symptoms may reemerge periodically, most people are able to adjust to the loss by this time. Unfortunately, a small subset of bereaved individuals never fully integrates the loss into their life, and continue to experience severe disruption in daily life even many years after the loss. The labels given to this condition have changed over the years, including pathological grief, traumatic grief, complicated grief and, more recently, prolonged grief. We decided to use the term “prolonged grief” (PG) for two reasons. First, it better expresses the nature of the disorder, characterised by the abnormal persistence of severe disabling symptoms related to the bereavement. Second, it is most likely that the revision of the International Classification of Disease (ICD-11), which is currently planned for approval by the World Health Assembly, will introduce a new diagnosis to recognise this clinical condition, using the label of Prolonged Grief Disorder (PGD).

However, the identification of this syndrome in the current psychiatric diagnostic systems has been much debated recently. Factor analytic studies have identified and isolated the specific PGD symptoms, indicating that it is...
distinct from other psychiatric disorders, such as anxiety, depression, post-traumatic stress disorder and adult separation anxiety. Based on these data, consensus criteria for PGD have been formulated. Nevertheless, the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), failed to include this diagnosis, relegating the complications of grief to the section “other specified trauma and stressor-related disorders”, under the label of Persistent Complex Bereavement Disorder (PCBD), with the explicit criteria listed under conditions requiring further study. The DSM-5 reluctance to recognise PGD as a full diagnosis is probably due to different reasons, such as the risk to pathologise normal grief responses, the risk to underestimate the influence of cultural and contextual variables on the variation of the manifestations of grief and the risk to place much emphasis on traumatic stress, which may result in misdiagnosing or not diagnosing individuals suffering from other common and severe mental disorders.

Contrary to DSM-5, the ICD-11 will likely include, within the proposed new group of “Disorders specifically associated with stress”, a separate diagnosis of PGD, as a condition characterised by a distinct psychopathology. The ICD Working Group has exposed different elements favouring the inclusion of this new diagnosis. First, studies have shown that the core symptoms of PG are distinguishable from symptoms of uncomplicated grief and are associated with significant consequences. In fact, PG can predict long-term functioning impairments, reduction of quality of life, risk for mental disorders and suicidality, as well as physical health problems (e.g. hypertension, cardiovascular disorders, immunological dysfunctions). Second, the risk of medicalisation of some non-pathological reactions of grief seems very limited: epidemiological data show that a PG diagnosis only applies to a minority (about 10% following normal circumstances of loss) of bereaved people who experience persistent impairment, with higher rates following disasters, violent deaths, or the death of a child. Moreover, population rates of PG are estimated between 2.4% and 4.8%. Finally, diagnostic requirements have been also drawn carefully taking into account the marked cultural variations in the manifestation of grief. Although more research is needed in this area, some studies have shown that PG is present across a range of cultures, including non-Western settings, as well as across the life span.

Controversies aside, a growing literature has outlined PGD as a nosological distinct entity, characterised by distinctive phenomenology, risk factors, aetiology, different response to treatment and adverse outcomes. In this paper, we aim to clarify psychopathological characteristics of PG in order to facilitate clinicians in identifying bereaved individuals who suffer from the syndrome and provide them with appropriate, timely and effective treatments.

The phenomenology of prolonged grief

According to the model proposed by Prigerson et al., PG includes two core clusters of symptoms: the first is related to separation distress (e.g. intensive yearning, strong desire of the beloved, constant state of concern linked to the memory of the loved one), and the second is related to traumatic distress (e.g. recurrent and intrusive thoughts about the absence of the deceased, sense of disbelief regarding the death, being angry or emotionally numb, tendency to avoid memories associated with the pain of loss). Bereaved people who suffer from PG typically have difficulty in accepting the reality of the death and in adapting to life without the deceased. They find themselves in a repetitive loop of intense yearning and longing, being unable to move forward in life. PG symptoms last over 6 months, can sometimes persist for years and negatively influence functioning and quality of life. PG symptoms also include anger, guilt, or blame regarding the death, lowered self-worth, inability to form new bonds or relationship with others and strong denial of the loss, which is accompanied by feelings of mistrust, bitterness and identity confusion. Overall, a significant preoccupation with the deceased is developed, with ruminations about circumstances or consequences of the loss, intense physical or emotional reactivity to reminders, avoidance of reminders, or compulsive proximity seeking (e.g., keeping reminders of the died person). This condition can lead bereaved individuals to be chronically disengaged from others and from the world, to believe that life is empty and meaningless without the deceased and that their intense pain will never end. For this reason, suicidal thoughts may occur and are usually related to the hope of being reunited with the deceased loved one. Some years ago, a panel of experts on bereavement approved a consensus list of shared symptoms, outlining the clinical features of PG. They proposed empirically a final diagnostic criteria set: bereaved individuals with PGD must experience yearning (i.e. physical or emotional suffering due to an intrusive unfulfilled desire for reunion with the deceased) and at least five of nine additional symptoms. The latter must persist for at least 6 months after the bereavement and be associated with functional impairment. Factor analysis studies have contributed to define the nature of PG and underlined its clinical meaningful dimensions. In a large sample of patients, using the 19-item Inventory of Complicated Grief, six clusters of symptoms were identified: “yearning and preoccupation for the deceased”, “anger and bitterness”, “shock
and disbelief”, “estrangement from other”, “hallucinations of the deceased” and “behaviour change, including avoidance and proximity seeking” 19. These factors did not perfectly align with those reported in a subsequent study, which examined the factor structure of PG using the 31-item Structured Clinical Interview for Complicated Grief and found five explanatory factors: “yearning and emotional pain”, “difficulty accepting the death”, “emotional numbness, loneliness and social disconnection”, “suicidal ideation and meaninglessness”, “avoidance and negative affect” 17. Although direct comparison is hampered by methodological differences, including the quite high rates of comorbidity with other mental disorders, the findings of the two studies have some overlap. We note, for example, that in both cases yearning is indicated as first factor, confirming the centrality of this element in the disorder. The factor analysis studies, integrating clinical insights with empirical data, have contributed to determining the constitutive symptoms of PGD, delineating it as a mental disorder that is distinguishable from other mental disorders such as major depressive disorder (MDD) and post-traumatic stress disorder (PTSD) 13 15 31. However, some PGD symptoms do overlap with some symptoms of MDD and PTSD, and comorbidity of PGD with MDD is not uncommon 32 33. Indeed, 50-60% of PG individuals also meet criteria for a major depressive episode 26 32. Likewise, some evidence has shown that pre-existing depression may predispose individuals to develop PG after the loss of a beloved one 5. Therefore, it may be difficult for clinicians to make a diagnostic distinction between these clinical conditions.

**How to distinguish PGD from MDD**

PGD and MDD both include symptoms such as sadness, crying, sleep disturbance and suicidal thoughts. However, several studies have shown important differences between the two disorders. First, they have a different aetiology. Whereas PGD specifically arises as a result of a loved one death, MDD can result from many causes and, in some cases, may even arise without a clear cause 5 19. Regarding symptomatology, PGD symptoms are more stable over time than MDD ones. Bereaved individuals with PGD experience a consistent yearning, while MDD does not typically involve yearning. Factor analysis studies have confirmed that yearning loads highly on a grief factor, but not on depression. On the contrary, sadness loads highly only on a MDD factor 13 34. A study on negative cognition among bereaved people have found that “being overwhelmed by the loss” is specific for PGD, but not for depression, and that they show loss-related avoidant behaviours, while MDD is characterised by a more global avoidance 35. Likewise, PGD may include feelings of survivor guilt, which is specifically death-related, whereas depression guilt is usually pervasive and multifaceted 19. In addition, suicidal thoughts are different: in PG they are most commonly based on the strong desire to reunite with the loved one, whereas depressed people tend to attribute them to pervasive hopelessness 19. Moreover, the two conditions are different in clinical correlates. In fact, some evidence suggests that PG is not associated with a change in electroencephalographic (EEG) sleep physiology seen in MDD 36. In a more recent study, it has been demonstrated that bereaved PGD patients present activation of dopamine circuits and reward-related neural activity in the nucleus accumbens in response to reminders of the deceased, while depressed ones have a reduced capacity of activation of the same pathways 37.

**How to distinguish PGD from PTSD**

Experiencing the death of a loved one may be a traumatic life-changing event. Both related to this severely distressing identifiable event, PGD and PTSD share some similarities, such as symptoms of emotional numbing, disruptive intrusive thoughts, avoidance, inability to function and difficult reintegration into society 19 29 38. However, several studies have shown that most individuals with PGD do not meet criteria for PTSD 31 33 39 40. In fact, phenomenological differences between the two disorders have been detected. First, the hallmark of PTSD is fear, while the dominant emotions associated with PG are yearning and sense of emptiness 29 30. Even when PTSD arises after a loss of a loved one, intrusive thoughts are fixated on the death event itself, whereas in PG bereaved individuals experience intrusive and voluntary thoughts about diverse aspects of the relationship with the deceased. Indeed, they do not show typical symptoms, such as flashbacks, nightmares, vivid intrusive recollections of the event 5. Although both disorders are characterised by memories that are maintained permanently over time, the emotional valence of the contents is different: negative for PTSD and bittersweet (negative and positive, often concurrently: the memories of the deceased may provide comfort, but can also stimulate pain as a reminder of what is lost) for PGD 30. In PTSD, the traumatic event generates a sense of threat and leads individuals to avoid internal and external reminders of the death, whereas in PG avoidance is consequently limited to those stimuli that serve as reminders of the reality or permanence of the loss. Moreover, hyperarousal symptoms in PTSD are frequent and are related to hypervigilance to threat, whereas in PGD they are rare and related to the loss of interpersonal regulators 19.

Sometimes the differences between PTSD and PGD may appear less evident, for example when the deceased one is a child or a victim of major disasters. In these cases, the feelings of injustice and anger over the circ-
cumstances of the death may be overwhelming, leading to a more severe grief and psychopathological status. However, a recent study conducted on 643 survivors from the Asian tsunami has confirmed that PGD is distinguishable from PTSD. In details, bereaved individuals with PGD have obtained significantly lower scores on avoidance, hyperarousal and intrusion at the Impact of Events Scale-Revised, compared to those who were experiencing PTSD symptoms.

Risk factors of prolonged grief

Several studies have focused on possible risk factors for PGD. In a multicentre US study, 19 possible risk factors were evaluated by administering the Bereavement Risk Questionnaire to 262 hospice coordinators. Professionals identified bereavement risk factors, such as perceived lack of caregiver social support (70%), caregiver history of drug/alcohol abuse (68%), caregiver poor coping skills (68%), caregiver history of mental illness (67%) and patient is a child (63%). More recent studies have confirmed a specific role of these determinants, and have identified other factors that may predispose an individual to develop PGD, such as female gender, low education, older age, low socioeconomic status and low social support both before and after the death. Research has also focused on the types of the relationship to the deceased, underlining that attachment issues are salient in creating a vulnerability to PG. There is a substantial evidence that individuals with PG have experienced a close kinship relationship with the deceased. The reason why the loss is particularly devastating is harbouring precisely to the perception that the relationship was satisfying, life affirming and identity-defining. Examining the correlation between marital quality and adjustment to the impending loss of a terminally ill spouse, it was suggested that security-increasing marriages and insecure attachment styles put spouses at risk for elevated prolonged grief symptoms.

Although the nature of the relationship is the most important variable for developing PG, the circumstances of the death can also play a role. Studies have confirmed that traumatic features of the death (e.g. sudden, violent, unexpected death), a lack of preparation, or difficult interactions with medical or other staff at the time of the death may predispose to PG. Loss of a child is also recognised as a powerful risk factor for PG.

A higher risk of PG is found in cancer patients’ caregivers who report a perceived general disapproval from others, longer duration of caregiving, and own medical disease history. In a prospective longitudinal study with 342 cancer patients’ caregivers, hospital deaths were associated with a heightened risk for PGD (21.6% vs 5.2% p = 0.02) compared with home hospice deaths, which may instead have a reduced risk.

Another important factor associated with PG is a previous psychiatric history of depression, anxiety or bipolar disorder, as well as a history of multiple trauma or losses. On the contrary, several investigators have found that spiritual belief systems may decrease the risk of developing PG. Regarding ethnicity, a small cohort study has reported interesting results: African Americans have a 2.5 times higher incidence of PGD than the Caucasian population. Further research is, however, needed on this issue.

Some recent studies have pointed out that psychometric scales, developed for the evaluation of symptoms of PG in the period preceding the death of their loved one, can be useful in predicting subjects at higher risk of post-loss PG. For example, in a palliative care setting, a higher score at the Complicated Grief Inventory (CGI pre-loss) was significantly associated with a PG diagnosis after the loss. Similarly, the Prolonged Grief-13 (PG-13), a validated risk assessment screening measure for PG, was useful in identifying people at high, moderate or low risk of developing PG after the death of their beloved. These data may have important clinical implications, prospecting the possibility to detect the population at risk for PG and to offer them interventions as early as possible.

The treatment of prolonged grief

Several studies have demonstrated that PG has a different course and response to treatment compared with normal grief and depression. Despite this, pharmacological trials in PG are scarce. Historically, the prescription of tricyclic antidepressants to bereaved individuals have been shown to be useful to improve depressive symptoms, but appeared less effective than placebo in ameliorating specific PG symptoms. More recent studies have indicated that dopamine reuptake inhibitors may induce only a moderate response, whereas selective serotonin reuptake inhibitors have shown significant improvements on PG symptoms.
interventions. This finding was confirmed in a more recent review: the authors have also argued that such interventions may even interfere with the “natural” grieving process. Nevertheless, some interesting data come from a recent study on an Internet-based therapist-assisted cognitive-behavioural intervention as a prevention measure of PGD in recently bereaved individuals, called Healthy Experiences After Loss (HEAL). This intervention was shown to be well-tolerated and effective in reducing the burden of significant pre-clinical PGD. Although further research is needed, the preliminary results look promising.

Moreover, psychotherapy specifically designed for PGD (named Complicated Grief Therapy - CGT) has been shown to be beneficial. This new psychotherapeutic model, drawn from attachment theory and with roots both in interpersonal and cognitive-behavioural therapy, includes a variety of loss- and restoration-focused techniques. It also includes techniques similar to prolonged exposure, which reduce PG severity, by promoting emotional processing of memories of the death. Shear et al. compared CGT with standard Interpersonal Psychotherapy (IPT) in a randomised trial with PG individuals. Higher response rates (51% vs 28%) and faster time to response were detected in the CGT group. In a recent replication and extension of the study, these findings were confirmed demonstrating that CGT, compared with IPT, conferred higher symptom reduction, faster response rate (70.5% vs 32.0%) and a greater persistence of the results at 6-month follow-up (100.0% vs 86.4%).

Several preventive intervention programs have been proposed to enhance adaptation to bereavement and reduce grief symptoms in order to prevent complications and mitigate long-term negative consequences of bereavement. Unfortunately, a meta-analysis examining the results of nine randomised controlled trials on preventive interventions to bereaved individuals at risk of developing PG did not show any effectiveness of these interventions. This finding was confirmed in a more recent review: the authors have also argued that such interventions may even interfere with the “natural” grieving process. Nevertheless, some interesting data come from a recent study on an Internet-based therapist-assisted cognitive-behavioural intervention as a prevention measure of PGD in recently bereaved individuals, called Healthy Experiences After Loss (HEAL). This intervention was shown to be well-tolerated and effective in reducing the burden of significant pre-clinical PGD. Although further research is needed, the preliminary results look promising.

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Conclusions

Experts in the field of bereavement agree in recognising PGD as a new diagnostic entity to be included in current psychiatric diagnostic manuals. PGD is in fact characterised by distinctive phenomenology, aetiology, risk factors, response to treatment and adverse outcomes. The current literature reveals significant advancements in research regarding this condition with important clinical implications. Healthcare professionals may favour early identification of the subset of individuals at risk for PGD, thus reducing the psychological impact of modifiable risk factors and providing them with an adequate psychosocial support. Furthermore, agreement on standardised criteria for PGD will allow clinicians and researchers to identify bereaved individuals who have developed PGD, directing them to specific treatments and preventing negative consequences. The need for further studies, especially double blind, randomised, placebo-controlled trials, is urgently needed in order to identify the most effective treatment modalities.

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