

Current Clinical Psychiatry *Series Editor: Jerrold F. Rosenbaum*

Eric Bui *Editor*

Clinical Handbook of Bereavement and Grief Reactions



Humana Press

Current Clinical Psychiatry

Series Editor:

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Clinical Handbook of Bereavement and Grief Reactions

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and Complicated Grief

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Chapter 1

Grief Reactions: A Sociocultural Approach

Rachel F. Rodgers and Russell H. DuBois

Introduction

Sociocultural theories consider the role of external agents in the shaping of individuals' attitudes and behaviors [1], including their reactions to loss and bereavement. This chapter will use a critical feminist ecological model as its grounding framework [2, 3] and consider how the different systems within which individuals are embedded may influence their grief reactions. These systems may be conceptualized as increasingly distal, concentric levels of influence that are embedded within a certain historical context (Fig. 1.1). The first level of influence, referred to as the *microsystem*, includes elements in the person's environment offering immediate, face-to-face interactions and influences including, in particular, the interpersonal environment (family, friends, etc.). The second, more distal level is the *exosystem*, including the local community at a broader level, as well as public policy. The third level of the model is the *macrosystem*,

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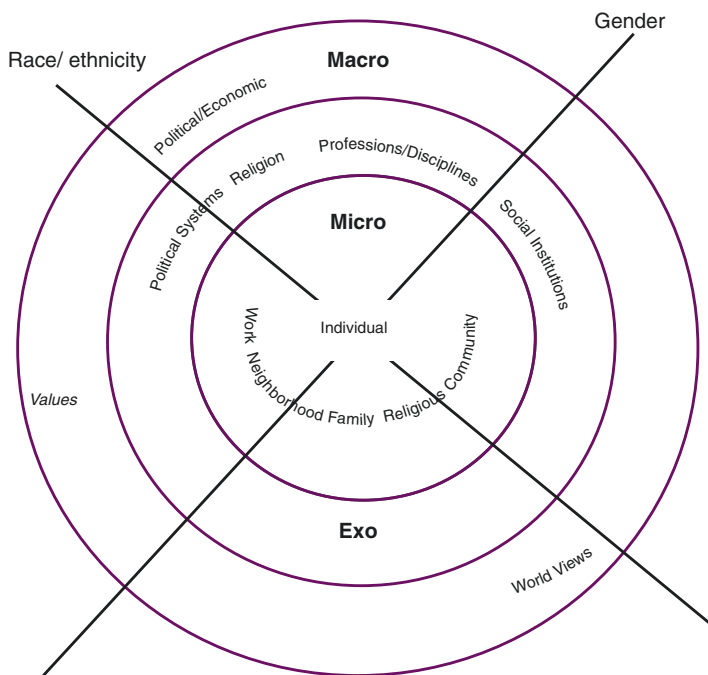


FIGURE 1.1 The critical feminist ecological model

including the economic and cultural context, and sociocultural agents such as the media. Each of these levels includes people or groups and organizations that may exert an influence on individuals' grief reactions. In addition, sociodemographic variables such as gender and ethnicity intersect with these systems and shape grief reactions in predictable ways. For example, the influence of the microsystem on grief reactions may differ between males and females or among racial groups. Thus, it is essential to consider not only the independent influence of each level on loss and grief, but the synthesized influence of each level at the various coordinates of intersection.

The aim of this chapter is to review the literature examining the relationship between sociocultural influences located

at different levels of this model and grief reactions, starting at the micro level and moving outwards towards more structural influences. In this way, we will discuss interpersonal influences and social constraints at the level of the microsystem, legislation/policy and religion at the level of the exosystem, and capitalism and Western values and the media at the level of the macrosystem. In addition, we will consider how social identity including gender and race/ethnicity are related to grief reactions and intersect at different levels of the model.

The Microsystem

Interpersonal Influence

In the context of loss and grief, the interpersonal influences that have been most examined have been within the family. According to the ecological framework, immediate family members are thought to have an important influence on the way in which individuals negotiate the processing of events such as loss and the ensuing grief [2]. This is because the family system often constructs the interpersonal context for loss and grief to take place. Consistent with this, recently, a shift has been observed from an individual understanding of the grief process towards an interpersonal interactive one, with a particular focus on family members [4, 5]. Within such a model it is acknowledged that grief may present differently for different family members, both in its intensity and its expression [6, 7]. However, this model also accounts for the existence of family-level processes and dynamics through which the grieving members reciprocally influence each others' grief process [4]. For example, the intensity of a parent's grief might influence the grief process in their child by impacting their parenting or their interactions with the child.

Nonfamilial social support constitutes another positive source of influence at the interpersonal level. Specifically, social support as a general construct is hypothesized to act as

a buffer from the potentially pathological influence of distressing life events such as loss [8, 9]. Two types of social support have been identified: on the one hand perceived social support from friends and relatives and on the other instrumental support, including organizational and financial assistance, etc. [9]. Perceived social support, that is the perception that one is included in a caring interpersonal network, has been found to be associated with less intense and shorter grief reactions [10, 11], perhaps due to the positive effect of social interactions on reengaging with life and the future. Likewise, instrumental supports such as direct financial assistance or material goods and services have also been found to be associated with less chronicity of grief [10, 12].

In contrast to these positive processes, authors have described the concept of disenfranchised grief that can occur when the circumstances are such that the individual's grief is judged illegitimate or inappropriate by either the griever or the social environment [13, 14]. In such a case, any grief reactions can be judged illegitimate by others regardless of their intensity or duration (as opposed for example to cases of prolonged grief that becomes viewed by others as inappropriate over time). Disenfranchised grief has been described in the context of relational distance from the deceased that is considered too wide (e.g., nonfamily member, or unrecognized affective ties), the characteristics of the bereaved individual are considered to exclude them from experiencing grief (e.g., the young and the elderly), or the circumstances of the death are thought to make grief illegitimate [13]. Importantly, this may prevent the griever from receiving the benefits of social support.

Social Constraints

Disclosure of emotional and cognitive experiences of grief constitutes an important component of healthy adjustment following loss. However, bereaved individuals often experience pressure to conform to societal norms that constrict the experience of grief rather than support it. Such a context may

hinder, or altogether restrict, an individual from disclosing loss-related thoughts and emotions, especially when they are negative in valence. For example, constrained social interactions may include instances of negative responses to repeated discussions of the loss or may consist of advice that attempts to minimize or otherwise fix the experiences of grief by encouraging reduction of grief reactions. Likewise, individuals may avoid talking about the loss with the aim of decreasing their grief, for example by avoiding rumination or exacerbating their symptoms. These actual or perceived interpersonal barriers to emotional disclosure are referred to as social constraints and manifest as limited opportunities to disclose thoughts and feelings in a supportive and validating context. Ultimately, social constraints create an interpersonal context whereby the bereaved feel alienated, unsupported, or otherwise misunderstood.

Negative consequences of social constraints on emotional adjustment and well-being have been identified among a number of distressing life experiences such as chronic illness [15], traumatic experiences [16], and loss [17, 18]. In the context of bereavement, disclosure of grief-related thoughts and feelings in a supportive and validating interpersonal environment is an important aspect of healthy adjustment following the loss. As such, high social constraints for loss-related disclosure are associated with higher depressive symptoms, somatic symptoms, perceived stress, and overall worse global health [17, 18], and moderate the relationship between loss-related intrusive thoughts and indicators of maladjustment [17]. Furthermore, longitudinal studies have indicated that social constraints 1 year post-loss exert negative effects on adjustment and emotional processing up to 3 years post-loss [18]. Such negative consequences are most typically understood using a Social-Cognitive Processing (SCP) model (see [19] for an overview of SCP and bereavement).

Importantly, social constraints intersect with other levels of the critical feminist ecological model, such as overarching Western beliefs on death and grieving influence individuals' responses to emotional processing and disclosure.

These beliefs include who has permission to be identified as the bereaved, how long grief should last, how grief is manifested, and if the manner of death is considered acceptable or is stigmatized [20]. For example, bereaved individuals typically believe that grief should last 3 months to 1 year post-loss, despite the fact that actual grief reactions can last much longer and may continue to manifest at important milestones throughout one's life [21]. Such beliefs create a socially constrained interpersonal context whereby the individual may be inclined to inhibit their discussion of loss, therefore having fewer opportunities to process their loss.

The Exosystem

Legislation and Policy

A number of aspects of legislation and policy may impact grief reactions in the aftermath of a loss, resulting from the various agencies and systems that interface with grief. In addition to national and local governance, these include bereavement agencies or more broadly the health-care system. These agencies may be involved in the development and evaluation of treatments aiming to support the grief process and reduce prolonged and chronic grief, including research institutes and bodies regulating drugs and medications.

One example of this, that will not be expanded upon here as it will be covered in detail in other sections of this work, is the emerging psychiatric diagnosis of “prolonged grief disorder” or “complicated grief” [22, 23]. The recognition of such a diagnostic entity has implications for the provision of services and allocation of resources to individuals experiencing more intense and chronic grief reactions. Furthermore, in the context of other mental health disorders such as eating disorders, it has been noted how symptoms presentation may change at the population level over the course of two decades, as clinical understanding evolves and symptom description

changes in disorder classifications [24]. In addition, similar to post-traumatic stress disorder, as a diagnosis, prolonged grief disorder or complicated grief is unique in that it implies causation and therefore in the legal context has the potential to become linked with issues of liability [25].

Another example of the influence of policy are the provisions of compassionate leave of absence, such as allowing an employee to receive paid leave following the death of a relative or close friend. Although the data on the impact of such policies on the experience of grief reactions are scant [26], they constitute an important influence on grief reactions through the implications for social support, both perceived and instrumental, disenfranchisement, and acknowledgement of the loss. On a more general level, policy deficits in compassionate leave invalidate griever's experience and convey the expectation that grief reactions must be suppressed or otherwise discarded. This message, coupled with the detrimental impact of such policies on the other domains of the exosystem mentioned above, is likely to negatively influence grief reactions in powerful ways.

Religion and Spirituality

Religion and spirituality play an important role in reactions to death and grief. Religious involvement has been conceptualized as a form of coping, and is often a positive one when it includes dimensions such as spiritual connectedness, a meaning to life, and a shared narrative around death and the afterlife [27, 28]. Consistent with this, greater use of spiritual activities was, for example, associated with lower symptoms of grief among bereaved parents [29]. One of the limitations of research in this field, however, has been that religious involvement often refers to a combination of beliefs, practices, and social support that may therefore affect grief reactions through various pathways. In this way, a systematic review of the relationship between spiritual and religious beliefs and bereavement was somewhat

inconclusive in terms of their impact [30, 31]. Thus, it has been suggested that examining the effects of internal beliefs and external community aspects on grief reactions separately might prove useful [32].

In terms of specific beliefs, the belief in a “just world” is often an important component of spirituality. It has been suggested that this belief may serve adaptive functions as a coping mechanism [33], and that this worldview may be helpful within the context of loss [12]. A number of theorists have highlighted the important role played by the process of finding meaning following a loss [34]. In fact, psychosocial interventions specifically targeting meaning making have been developed to support grievers (see Chap. 8). Beliefs in a “just world” and the capacity to integrate loss into a broader meaningful narrative may support an adaptive grief process.

Furthermore, religion and spirituality provide a context for changing one’s relationship to death and loss [27]. For example, many religions view life and death not as finite but as an ongoing process of carrying on one’s spirit. In such a context, the emotional and cognitive processing of death is fundamentally different than that of beliefs of life and death as finite states. In this same way, certain groups of individuals, such as young children, may benefit from the influence of religious or spiritual understandings of loss when they may not be able to adequately understand and process death and dying in finite terms [35].

The Macrosystem

Capitalism and Western Values

The Western political and economic systems are related to a number of underlying values and beliefs that are relevant in the context of an examination of grief reactions. At their core, these systems are based on the notion of individuals as consumers within a model of constant growth. In this way, individual worth is tied to materialistic indices and values [20].

Death is increasingly hidden, avoided, and unwelcome in a context in which fulfillment is to be sought through consumption and gain (which, importantly, is literally the opposite to loss), as well as control over one's life. This denial of death results in its disappearance from rituals and social interactions, as well as a nonacceptance of death. Relatedly, Western society is characterized by high levels of avoidance of negative emotions, which has been shown to be associated with a focus on materialism [36]. In this way, negative affect even when experienced is unwelcome, poorly tolerated, and considered to interfere with "moving forward" and productivity. This avoidance of the emotional processing of grief may also paradoxically increase the risk of prolonged grief disorder or complicated grief through experiential avoidance [37].

As described above, the disenfranchisement of grief has been described as a contemporary process and is linked to changes in Western society [14]. The focus on economic growth has been associated with a decrease in rituals and social interactions surrounding death, and the progressive restriction of the circle of individuals who partake in any symbolic marking of death. Grieving is both practically (through loss of productivity) and symbolically incompatible with a capitalistic growth model [20]. In addition, death implies a loss of control, a failure to overcome and to achieve that is at odds with capitalist values. This context leads to what has been termed the "oppression" of the bereaved [20], which discourages the expression of grief and isolates those who are grieving.

The denial of death as imminently possible and eventually inevitable, lack of preparedness for the death of a loved one, and then lack of acceptance of such a death are all congruent with Western values, and obstacles to the mourning process. Some authors have described lack of acceptance of a loss as a symptom of grief [38], and later suggested that acceptance and grief might be diametrically opposed, such that as one increases the other decreases by equal measure [39]. Consistent with this, acceptance of a loss has been shown to protect from chronic and persistent grief [12].

Media

In sociocultural theories, media has been described as a sociocultural agent, Media as agent, and a source of information regarding sociocultural norms [40]. In this way, it perpetuates social scripts and norms and contributes to the socialization of individuals, in particular youth, into cultural codes and norms. In particular, it has been highlighted how the fact that experiences around death are relatively infrequent for most individuals increases the importance of media as a source of information on this topic [41]. Media is an important form of socialization regarding death, loss, grief, and normal grief reactions, allowing individuals to learn about death and grief indirectly [42].

However, in addition to being a reflection of social and cultural constructs, in Western society media represent a for-profit force in its own right, and in this way also actively create sociocultural discourse. The “speeding up” of contemporary society, and importantly the contemporary consumer, has been described as leading to an increase in sensationalism in the media in an attempt to maintain consumer attention, in particular through increasingly violent and sexually explicit content [43, 44]. Violence has become highly prevalent in televised media content including both news programming and films [45, 46]. In this context, the number of deaths depicted within media, and in particular violent deaths, has also increased [41]. The term “pornography of death” [47] was coined to refer to the process by which natural death has become “unmentionable,” hidden and shameful, violent death on the other hand has become increasingly publicly depicted.

These frequent and violent media deaths have further been shown to occur in the absence of any grief reactions [41]. Such depiction of an absence of grief reactions in response to (violent) death may suggest to audiences that this is the appropriate response to a loss. Similar framings have been found in films created for children, with the death of villains in particular associated with no emotional acknowledgement from the other characters [48]. Thus for example,

Scar from the *Lion King* is not mourned by the other characters, in contrast to *Mufasa* (the protagonists' father) whose death has a clear emotional impact on the characters. The omission of the emotional impact of loss in media portrayals of death may increase perceptions among the general public that grief reactions are abnormal, or at least should not be displayed. In this way, the influence of the media coupled with the dominant Western values of death as unwelcome and hidden exerts a repressive influence on individuals' grief reaction.

Gender and Ethnicity

Gender Roles

Gender influences on grief reactions can be more broadly situated with social gender scripts regarding emotional expressiveness and relational styles [49]. Thus, the ways in which different genders are socialized within Western society influence the ways in which grief is experienced, communicated, and adapted to [50].

From a social constructionist perspective, that is a lens that places emphasis on the way in which individuals co-construct reality rather than its extrinsic existence, gender is performed [51]. Furthermore, recent theorists have emphasized the precarious nature of contemporary masculinity and how this may influence coping and outcomes [52]. Western masculinity is associated with more limited emotional expressiveness, but more importantly, the permission to express certain types of emotions more than other, thus for example anger is considered to be a more masculine emotion than sadness [53]. Similarly, masculinity is associated with active and instrumental coping styles and responses (e.g., exclusive focus on post-loss arrangements and related services), as opposed to more relational and emotional ones. Thus, characteristically masculine grief responses may place an emphasis on action, constructive actions, and restoration [53].

In contrast, Western femininity is less tenuous and easily lost, and also more readily obtained [52]. In this way, femininity can be performed through self-presentation and is not considered to be precarious or need to be repeatedly proved in the way that masculinity is. Femininity is associated with greater emotional expressiveness including a range of emotions such as sadness, loss, and helplessness. Characteristically feminine responses to loss may therefore be more loss-oriented, and emotionally based, acknowledging the contribution of relationships to the construction of feminine identity [53]. Such gender-related patterns should not be considered to be gender-specific and exist along a continuum in the same way as other gender-role related dimensions.

It is important to note the existence of what has been termed a Western bias towards emotional expressiveness, suggesting that Western people tend to hold a positive bias towards openly expressing affective states [49]. Consequently, this bias leads to a view among Western society that a feminine mode of experiencing grief is most adaptive. More recently, however, authors have highlighted how different patterns of grief reactions may be equally adaptive and present their own strengths for resilience and growth [49].

Race and Ethnicity

Within the critical feminist ecological model, race and ethnicity are considered to be dimensions that moderate the effect of different spheres of influence, similar to the way in which gender does. The emphasis is therefore on considering how belonging to various groups may provide increased or decreased power and privilege in relation to some of these influences, and how identifying and being identified as a member of a certain group may modulate the processes described above, here in the context of grief reactions.

To date, only a limited body of research exists examining the intersection of race/ethnicity and grief reactions; however,

one group that has received attention is the African-American individuals. It has been noted that a number of factors may contribute to a specific set of grief reactions in African-American individuals, including the increased likelihood of experiencing traumatic death, shorter life expectancies, and overall lower access to resources and services as compared to White individuals, as well as the context of oppression, racism, and other stressors that may shape grief reactions [54]. A number of authors have suggested the establishment of culturally specific models of the grief process, accounting for dimensions including spirituality and a more collectivistic orientation [55, 56]. In addition, among African Canadians, who share a number of the aforementioned characteristics with African-Americans as pertains to grief, racial stratification and attitudes related to violent death increased the likelihood of grief being experienced as disenfranchised and invalidated, which may impede the grief process [57].

Another group that has received some attention with regard to culturally specific grief reactions is the Latino/a population. Latino/a individuals may experience similar socio-cultural stressors to other minority groups such as African-Americans [58]. In addition, some research has suggested that across different types of loss, Latino/a individuals may display more intense grief reactions as compared to their White counterparts [59]. Furthermore, culturally specific understanding of grief in Latino populations are clearly also warranted and may include an emphasis on the continuation of family bonds beyond death and the notion of extended family.

Racial and ethnic groups may therefore differ in the way they react to loss, and the grief process. It is important to recognize, however, that cultural groups are frequently not homogeneous, and that individuals' cultural identities should be taken into consideration [60]. Furthermore, little is understood of the way multiple minority identities may intersect as they pertain to grief reactions, and particularly how this might impact experiences of disenfranchised grief.

Conclusions

In conclusion, the critical feminist ecological model provides a useful framework within which to explore the different levels of sociocultural influences that may impact grief reactions. These include interpersonal influences and social constraints at the level of the microsystem, legislation/policy and religion at the level of the exosystem, and capitalism and Western values and the media at the level of the macrosystem, in addition to the intersecting dimensions of gender and race/ethnicity. Overall, the work reviewed in this chapter suggests that developing practices that can contribute to recognizing, and legitimizing grief, as well as authorizing emotional expression and experiences around loss may be helpful. Further investigations into ways in which individuals can be empowered to change norms around grief are warranted.

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Chapter 2

Grief and Post-Traumatic Stress Following Bereavement

Madelyn R. Frumkin and Donald J. Robinaugh

Introduction

The death of a loved one is among the most painful and disruptive events many of us will face over the course of our lives. The grief that follows bereavement can be profound, often described as coming in intense waves or pangs that are interspersed with an enduring sense of absence, emptiness, and loss of meaning. Although there is neither a predetermined set of stages by which grief progresses nor a timetable it must follow, the frequency and intensity of bereavement-related distress does tend to subside over time for most bereaved adults [1].

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For some, however, the psychological effects of bereavement do not improve with time, remaining severe and impairing. When this distress persists long after the death and the ability to function effectively at home, socially, or at work remains compromised, some bereaved adults choose to seek support from mental health professionals.

For clinicians working with these bereaved adults, the first step toward creating a treatment plan is assessing for the presence of psychiatric disorders and formulating a case conceptualization. Bereavement increases risk for numerous psychiatric disorders, so a thorough diagnostic assessment is necessary. However, the disorders most commonly associated with bereavement are depression, post-traumatic stress disorder, and complicated grief [2]. Among these, it can be especially difficult to disentangle the presence of post-traumatic stress disorder and the presence of complicated grief, disorders that share considerable phenomenological overlap and are unique in the DSM by virtue of being tied to a specific etiological event. Consider three vignettes inspired by bereaved patients we have seen in our clinic (names and details of these stories have been modified to protect patient confidentiality).

Deborah is a 45-year-old woman reporting intense and impairing distress tied to the death of her son. Four years ago, Deborah and her son were the victims of an armed robbery. The assailant shot at and struck both Deborah and her son. Deborah survived, but her son died instantly. In the years following the loss, Deborah's grief has remained intensely painful. She returned to her job several months after the death, but was unable to concentrate on her work, continuously distracted by thoughts about the death and waves of intense grief. After several weeks, she left her job and has been unable to return to work since. Although friends and family were very supportive in the initial months following her son's death, she avoids talking to them about the loss and has begun to feel distant and cut-off from the people in her life. She denies experiencing any fear or anxiety about similar events happening in the future, and she denies heightened physiological reactivity or hypervigilance for danger in her

surroundings. Instead, she feels a discomforting numbness interrupted only by a yearning to be with her son again and an intense guilt stemming from the belief that she failed to protect him from harm. Deborah experiences persistent suicidal thoughts and frequently uses alcohol in the evenings, wishing for anything that will relieve her pain.

Joan is a 52-year-old woman who was recently hospitalized due to debilitating grief that arose in the days leading up to the anniversary of her father's death. Two years ago, her sister passed away after a years-long battle with cancer. Only weeks later, Joan's father collapsed in his kitchen, overcome by intense chest pain. By the time Joan arrived at the hospital, he had been declared dead. Joan reports overwhelming pain when reminded of his absence and an intense urge to be with and talk with him again. She is haunted by memories of her father's face when she saw him in the hospital and dreads going to bed for fear of having nightmares about her father's death. She frequently ruminates about what she could have done to prevent the loss. In addition, she reports that she no longer believes the world is a safe place; feeling that if her father died so suddenly, danger and death could occur at any moment. She has difficulty sleeping and is always on guard, expecting disaster at every turn.

Matt is a 36-year-old man seeking treatment for distress tied to a severe car accident he experienced two years ago. Matt had been in the passenger seat when his wife ran a stop sign and drove into the path of an oncoming truck. His wife was pronounced dead at the scene, while Matt was taken to a nearby hospital to be treated for minor injuries. In the years following the accident, Matt has continued to raise their two young children and, while he misses his wife deeply, he does not consider grief over their relationship to be his primary source of distress. Instead, he reports intense distress around the accident itself, including nightmares and intrusive memories of seeing the approaching truck moments before the accident. Since the accident, Matt has been so afraid of being in another car accident that he refuses to drive on anything

but local residential roads and experiences great anxiety on the few occasions he lets others drive him places that requires getting on the highway. He ultimately moved into an apartment in the city so that driving is rarely necessary, and his parents assist with getting the children to school and other activities as needed. Although his boss had been flexible with him in the months following the accident, Matt was recently put on a performance improvement plan and believes he is at risk of losing his job if he is not able to resume a normal travelling schedule.

Did these patients experience bereavement or trauma? Are they now experiencing complicated grief or post-traumatic stress disorder? What is the most appropriate case conceptualization for these patients and what treatments are most appropriate? In this chapter, we aim to provide information about complicated grief and post-traumatic stress disorder that can help guide these decisions. We begin by providing a brief overview of the historical development of the complicated grief and post-traumatic stress disorder diagnoses in order to provide an appreciation for the extent to which these syndromes are, and always have been, closely related. We then conclude with considerations for how to assess, conceptualize, and treat complicated grief and post-traumatic stress disorder in the clinic.

The History of Complicated Grief and Post-Traumatic Stress Disorder

The Cocoanut Grove Disaster: Bereavement or Trauma?

On Saturday, November 28, 1942, an estimated 1000 people filled a popular Boston club, more than doubling its legal capacity. Late in the evening, a small fire began in one of the palm tree decorations of the club known as Cocoanut Grove. The flames spread rapidly through other decorations, filling

the club with fire and toxic gas. As the fire spread, panicked guests forced their way toward the exits of the overcapacity club and many were trapped by locked doors and exits forced shut by the crush of people attempting to escape. Ultimately, 492 people died and 166 more were injured in what remains one of the deadliest fires in American history [3].

In the aftermath of the Cocoanut Grove fire, a psychiatrist at Massachusetts General Hospital named Erich Lindemann interviewed individuals who had experienced the death of a loved one in the fire, including some who had themselves been in the club and had experienced significant threat to their own lives. These interviews became part of the first empirical study of grief, published 2 years later in the *American Journal of Psychiatry* [4]. In this seminal study, Lindemann described grief as a “remarkably uniform” syndrome that included waves of intense somatic distress and mental pain, preoccupation with thoughts about the death, restlessness, grief-related avoidance, and feelings of guilt and social isolation ([4], p. 187). This descriptive account of grief was highly influential (as of 2016, it had been cited more than 4300 times) and laid the foundation for our current understanding of grief.

Interestingly, Lindemann was not the only researcher who studied the psychological toll of the Cocoanut Grove disaster. Over the course of the first year following the fire, Alexandra Adler, a psychiatrist at Boston City Hospital, studied the “post-traumatic mental complications” of more than 100 victims of the fire who were treated at Boston City Hospital. The experiences of these survivors were harrowing. Many had been severely injured or had lost consciousness as toxic gas and smoke filled the club. Notably, more than half had experienced the death of a friend or relative in the fire. In 1943, Alexandra Adler published a report of the neuropsychiatric complications of these survivors in the *Journal of the American Medical Association* [5]. Although less widely known than Lindemann’s seminal work, Adler’s research also proved to be influential. Her description of patients who experienced preoccupying thoughts about the event, terrifying

nightmares, depressed mood, feelings of guilt, “general nervousness,” irritability, fatigue, and insomnia are immediately recognizable as the syndrome we now refer to as post-traumatic stress disorder (PTSD). Indeed, Adler’s work was among the first to systematically describe the PTSD syndrome in a civilian population and influenced the formation of PTSD diagnostic criteria when it first emerged as a diagnosis in 1980 with the third edition of the Diagnostic and Statistical Manual (DSM-III).

Lindemann and Adler both studied survivors of the Cocoanut Grove fire, many of whom who had faced both a threat to their own lives and the death of a loved one in the fire. One described the syndrome they observed as grief, whereas the other labeled the syndrome as post-traumatic mental complications. These two conceptualizations would go on to influence the development of two distinct mental disorders, one focused on the psychological consequences of bereavement and the other on the consequences of trauma. Yet, the syndromes reported by Lindemann and Adler have considerable overlap and are based, in part, on samples that were exposed to both bereavement and trauma. These early studies in the history of grief and post-traumatic stress reactions illustrate the extent to which the two have been closely intertwined since the earliest empirical research on these conditions, and they raise a fundamental question: How do we as clinicians and clinical researchers distinguish between grief and post-traumatic stress?

PTSD in the DSM

Although PTSD is a well-established diagnosis today, in the 1970s its proposed inclusion in the DSM-III faced considerable opposition. This opposition was overcome, in part, by the intense lobbying efforts of a group of psychiatrists and activists working in support of veterans of the Vietnam War (for a review of the historical development of PTSD, see [6]). These psychiatrists, led by Chaim Shatan and Robert Lifton,

believed that the inclusion of a “post-Vietnam syndrome” in the DSM was critical to calling attention to and receiving resources to address the psychological toll enacted by the Vietnam War. Their advocacy was bolstered by researchers studying responses to other highly stressful life events, including burn victims and survivors of the holocaust. Among these, perhaps the most influential was the psychiatrist Mardi Horowitz. Drawing in part on Lindemann’s account of grief following the Cocoanut Grove fire, Horowitz had formulated a theory of stress response syndromes, a framework for understanding the psychological consequences that follow highly stressful life events and the forces that lead those consequences to persist over time [7]. Central to Horowitz’s theory was the assertion that many stressors will evoke significant symptoms in the majority of individuals. Although pre-existing factors such as personality features may exacerbate the stress response, the syndrome was attributable to the stressor itself, rather than solely to vulnerability factors. Horowitz’s work on stress response syndromes provided a firm empirical backing for the political pressure applied by Shatan and Lifton and, together, they persuaded the DSM committee to include PTSD in the DSM-III.

The influence of Horowitz’s stress response theory is readily apparent in the DSM-III PTSD diagnostic criteria. The intrusive memories, re-experiencing of the trauma, and trauma-related avoidance symptoms that are now hallmarks of PTSD were present in Horowitz’s writings years earlier. However, in a significant departure from Horowitz’s theory, the DSM committee added a stipulation that the stressful events precipitating the symptoms (i.e., the trauma) must be “outside the range of usual human experience,” thereby excluding “such common experiences as simple bereavement” ([8], p. 247). Neither Horowitz nor Shatan and Lifton drew such a distinction between trauma and bereavement in their work that led up to the PTSD diagnosis. Indeed, bereavement and grief were each featured prominently in their work. Shatan described post-Vietnam syndrome, as the “the unconsummated grief of

soldiers,” noting that “...much of what passes for cynicism is really the veterans’ numbed apathy from a surfeit of bereavement and death.” ([9], p. 648). Similarly, Horowitz drew no distinction between bereavement and other stressors in his description of stress response syndromes, arguing that the most common precipitants of stress response syndromes included “injury, assault, or loss of a loved one” ([10], p. 241).

The definition of trauma in the DSM-III raised an important question that set the stage for how we interpret trauma and bereavement today: What falls within the bounds of “usual human experience”? Given that the vast majority of people will experience the death of a loved one at some point in their lives, it seems clear that bereavement in and of itself is well within the bounds of “usual human experience.” However, the boundaries containing “usual” become quickly muddled when considering the details of a specific patient’s loss. Is it within the bounds of usual human experience to lose a child to cancer? Is it usual to lose an elderly father to suicide? The vague and undefined term “simple bereavement” provided clinicians little further guidance as to when the deaths described by their patients should be considered a trauma.

In the fourth edition of the DSM (DSM-IV), the DSM committee attempted to clarify the issue, stipulating that a diagnosis of PTSD following bereavement should be given only in the context of the “sudden, unexpected death of a family member or close friend” ([11], p. 463). The new criteria also stated that “learning that one’s child has a life-threatening disease” should qualify as a traumatic event ([11], p. 464). The rationale behind designating “sudden and unexpected” bereavement as uniquely traumatic was unspecified, but may have been tied to research demonstrating that sudden and unexpected loss was capable of eliciting the PTSD syndrome. Indeed, in a study of over 2000 individuals in the Detroit area, epidemiologist Naomi Breslau found that the sudden and unexpected death of a

loved one was the most commonly reported trauma among those with PTSD [12]. In other words, if an individual was experiencing PTSD, the most likely precipitating event was sudden and unexpected loss of a loved one. This study did not assess for the presence of PTSD following other types of bereavement, thereby making it unclear if similar rates of PTSD would be observed following other types of losses. However, it did provide strong support for the notion that sudden and unexpected loss was an event important to our understanding of PTSD.

It is perhaps surprising then that in the DSM-5, the guidelines for when bereavement qualifies as trauma was modified again, restricting inclusion to only those instances of “violent or accidental” death ([13], p. 271). The death of a child to cancer no longer qualified as a trauma, nor would the sudden and unexpected loss of a spouse due to illness. As with previous editions of the DSM, no evidence was provided to support this modification. Nonetheless, the result is that most instances of bereavement do not qualify as a traumatic event, thus precluding the diagnosis of PTSD.

Complicated Grief in the DSM

In the 1990s, Mardi Horowitz and his colleagues responded to this exclusion of most bereavement from the PTSD diagnosis by calling for a new diagnostic category that would address those with chronic distress following bereavement. As previously noted, Horowitz significantly shaped our understanding of post-traumatic stress reactions with his work on stress response syndromes, and he explicitly and prominently included bereavement in the category of stressors capable of eliciting this syndrome. Observing that the PTSD diagnosis excluded many of those chronically struggling with the death of a loved one, he proposed a “pathological grief” disorder

rooted in this theory of stress response syndromes. Horowitz's "pathological grief" criteria included intrusive memories, social withdrawal, inability to return to normal daily life, loss of connection with others, fatigue, and other somatic symptoms—all symptoms that appear in his descriptions of stress response syndromes and in the diagnosis of PTSD.

In the subsequent decades, the "pathological grief" diagnosis has been subjected to considerable empirical scrutiny and, in the DSM-5, the syndrome was included for the first time under the name Persistent Complex Bereavement Disorder (PCBD) as a condition in need of further study. As reviewed in Chap. 2 of this book, the diagnostic criteria for this diagnosis have evolved since Horowitz's initial proposal, and a variety of terms have been used to refer to the syndrome, including traumatic grief, prolonged grief, and complicated grief (the term we use here). However, the syndrome remains very much rooted in the same formulation of stress response syndromes that was so influential in the development of the PTSD diagnosis, contributing to the substantial overlap in these syndromes that we see today.

Considerations for Assessing CG and PTSD in the Clinic

The historical development of the CG and PTSD diagnoses illustrates the close relationship between these syndromes and the difficulty disentangling them in individuals who have experienced the death of a loved one. Compounding this problem, there has been relatively minimal research aimed at providing guidance for clinicians about how best to assess and treat patients who present with distress resulting from an event that does not fall cleanly into the category of trauma vs. bereavement. In the remainder of this chapter, we will identify issues relevant to assessing and treating CG and PTSD in the clinic that can guide clinical decision-making and provide directions for future clinical research.

Assessing Trauma

As is evident from the evolution of the PTSD diagnostic criteria in the DSM, attempts to define a boundary between PTSD and bereavement-related disorders have relied heavily on drawing a distinction between trauma and bereavement. Implicit in this distinction is the notion that some types of bereavement are not traumatic. However, when put into practice, this distinction between traumatic and nontraumatic loss is often difficult to discern.

Consider, again, our clinical vignettes—Deborah, who witnessed the shooting death of her son and experienced significant threat to her own life; Joan, whose elderly father died suddenly of heart failure in the weeks following her sister's death; and Matt, who was involved in a severe car accident in which his wife died immediately. Each of these patients experienced the death of a family member and each is seeking treatment more than a year following the death. Did these patients experience a traumatic event?

Deborah's loss would meet diagnostic criteria for a traumatic event across all versions of the DSM PTSD diagnostic criteria because she also experienced significant threat to her own life in the event. Even if she had not experienced this direct threat to her own life, most would agree that her son's death was "outside the range of human experience" (DSM-III), was sudden and unexpected (DSM-IV), and was violent (DSM-5), thus qualifying it as a trauma across all editions of the DSM. Similarly, Matt's loss would meet diagnostic criteria for a traumatic event across all versions of the DSM by virtue of the direct threat to his own life. Considering only the loss itself, losing a loved one in a deadly car accident would presumably be considered "outside the range of human experience" by most (DSM-III), and was certainly sudden (DSM-IV) and accidental (DSM-5), suggesting that Matt's experience of bereavement would also meet diagnostic criteria for a traumatic event across each iteration of DSM PTSD criteria.

Joan's case is less clear. Under DSM-III, many would likely conclude that the death of her father would be considered within the range of "usual human experience" given his age and the nature of his death, thereby excluding this death from qualifying as a traumatic event. With revisions adopted in the DSM-IV, however, Joan would be considered to have experienced a traumatic event, as her experience precisely matches the required "sudden, unexpected death of a family member or close friend." Yet, 13 years later, the DSM-5 revised the trauma criterion and stipulated that the death must be "violent or accidental," thereby removing Joan's eligibility for a PTSD diagnosis. As is often the case, the details of the loss Joan experienced blur the hard lines drawn in the DSM. Joan experienced the death of her father only following the death of her sister, an experience that perhaps falls less clearly into the category of "usual human experience" than if her father's death had occurred as an isolated event. Similarly, the characterization of his death as nonviolent belies the nature of death due to sudden illness, which often involves witnessing a loved one in highly distressing circumstances (e.g., violent seizures) or receiving aggressive interventions aimed at saving the person's life. In Joan's case, she was highly troubled by intrusive thoughts about her father's death and the intense pain she believed he must have been in, despite this event not meeting diagnostic criteria for a traumatic event in the current edition of the DSM.

As Joan's case illustrates, the line between bereavement and traumatic bereavement is often unclear. In large part, this lack of clarity arises from the fact that there is no agreed upon definition of what it means for an event to be traumatic, nor a general objective measure of trauma severity [14] that would inform a distinction between traumatic and nontraumatic bereavement. This vagueness has almost certainly contributed to the shifting lines drawn around the types of events that qualify as traumatic.

Assessing CG and PTSD Symptoms

Before reviewing our assessment of symptoms for each of our case examples, it is important to consider the similarities and differences between CG and PTSD symptoms. The table below displays the symptoms of PTSD and CG as enumerated in the DSM-5. There is substantial overlap between the two syndromes. Many symptoms are included in the diagnostic criteria for both CG and PTSD, including preoccupying thoughts about the death, avoidance, negative beliefs about oneself or others, negative emotional states, and feeling detached from others. In some cases, the overlapping symptoms are identical (e.g., avoidance of thoughts related to the death). In other cases, two symptoms may share similar themes, but are nonetheless distinguishable constructs. For example, while PTSD may be characterized by self-destructive behavior, CG may involve a desire to die in order to be with the deceased. The theme of self-harm is present in both; however, the CG symptom is more narrowly defined, requiring a motivation tied specifically to grief (Table 2.1).

Yet despite this substantial overlap, there are noteworthy differences. PTSD is characterized principally by thoughts and memories related to the traumatic event (i.e., the death in the case of bereavement), avoidance, and alterations in physiological arousal and reactivity. Together, symptoms from these domains make up 14 of the 20 PTSD symptoms, and these symptoms are a primary focus of PTSD treatments. In contrast, thoughts and memories in those with CG include not only thoughts related to the death, but also of the deceased. Similarly, avoidance is not only tied to the death, but also to reminders of the deceased and their absence. The symptoms of heightened arousal so prominent in PTSD are largely absent from diagnostic criteria for CG. Conversely, CG criteria include many symptoms not highlighted in PTSD diagnostic criteria, such as a lost sense of meaning or purpose, confusion about one's identity, and difficulty imagining one's personal future. Importantly, the absence of a symptom from a diagnostic criteria set does not mean that the symptom is

TABLE 2.1 Post-traumatic stress disorder and complicated grief symptoms as enumerated in the DSM-5

	Post-traumatic stress disorder	Complicated grief
Memories and thoughts related to the death and the deceased	<ul style="list-style-type: none"> • Recurrent, involuntary, and intrusive distressing memories of the trauma • Recurrent distressing dreams related to the trauma • Dissociative reactions (e.g., flashbacks) • Intense or prolonged psychological distress at exposure to reminders of the trauma • Marked physiological reactions to reminders of the trauma • Inability to remember important aspects of the trauma 	<ul style="list-style-type: none"> • Preoccupation with the deceased • Preoccupation with the circumstances of the death • Difficulty with positive reminiscing about the deceased
Avoidance	<ul style="list-style-type: none"> • Avoidance or efforts to avoid distressing memories, thoughts, or feelings related to the trauma • Avoidance or efforts to avoid external reminders (people, places, situations) 	<ul style="list-style-type: none"> • Excessive avoidance of reminders of the loss (e.g., individuals, places, or situations associated with the deceased)
Emotion and mood	<ul style="list-style-type: none"> • Persistent negative emotional state • Loss of interest in significant activities • Persistent inability to experience positive emotions 	<ul style="list-style-type: none"> • Persistent yearning/longing for the deceased • Intense sorrow and emotional pain • Bitterness or anger related to the loss • [Disbelief or] emotional numbness over the loss

TABLE 2.1 (continued)

	Post-traumatic stress disorder	Complicated grief
Thoughts and beliefs about oneself, one's future, or the world	<ul style="list-style-type: none"> • Distorted cognitions that lead to blaming oneself or others • Persistent and exaggerated negative beliefs or expectations about oneself, others, or the world 	<ul style="list-style-type: none"> • Maladaptive appraisals about oneself (e.g., self-blame) • Difficulty or reluctance to pursue interests since the loss or to plan for the future • Feeling that life is meaningless or empty without the deceased, or the belief that one cannot function without the deceased • Confusion about one's role in life, or a diminished sense of identity
Social disconnection	<ul style="list-style-type: none"> • Feeling detached or estranged from others 	<ul style="list-style-type: none"> • Feeling alone or detached from others • Difficulty trusting others since the death
Alterations in arousal and reactivity	<ul style="list-style-type: none"> • Verbal or physical aggression • Reckless or self-destructive behavior • Hypervigilance • Exaggerated startle response • Problems concentrating • Difficulty sleeping 	

(continued)

TABLE 2.1 (continued)

	Post-traumatic stress disorder	Complicated grief
Difficulty accepting the loss		<ul style="list-style-type: none"> • Marked difficulty accepting the death • Disbelief [or emotional numbness] over the loss
Suicidal thoughts		<ul style="list-style-type: none"> • A desire to die in order to be with the deceased

Note. The symptoms listed for complicated grief here are the diagnostic criteria for the syndrome in the DSM-5, where the syndrome is referred to as Persistent Complex Bereavement Disorder. The categorization of symptoms here is based solely on our interpretation of the symptoms and is not drawn from the DSM-5 or from any statistical analyses

not part of the phenomenology of the disorder. Indeed, many of the symptoms present in one of these disorders (e.g., difficulty imagining one's future in CG) have also been observed in those with the other disorder (e.g., a sense of foreshortened future in PTSD). Nonetheless, the non-overlapping symptoms in PTSD and CG suggest that failing to assess one of these disorders following bereavement may limit one's understanding of what the patient is experiencing and, thus, may hinder efforts to form an appropriate case conceptualization and treatment plan; a possibility illustrated in our clinical vignettes.

Deborah endorses several symptoms of PTSD regarding the death of her son, including frequent and intrusive thoughts about the death, emotional reactivity to reminders of the event, emotional numbness, a sense of foreshortened future, and a feeling of being distant or cut-off from other people since the event. However, she does not report hypervigilance, hyperarousal, or difficulty sleeping. She does not feel that the world was a dangerous place and did not fear events like the

one she experienced happening to her again. When she gets lost in intrusive thoughts about the event, her focus is not on the threat to her life, but on her perceived failure to protect her son. Instead of reacting to these memories with fear or horror, she reports intense guilt. She reports that her most intense emotional experience is yearning to be with her son again and a deep sense of emptiness without him. Based on her reporting of these symptoms, a full diagnostic interview would reveal that Deborah meets criteria for CG, but not for PTSD.

Joan yearns for her father, feels overwhelming waves of pain when reminded of his absence, and was hospitalized in the days leading up to the anniversary of his death due to an inability to cope with the overwhelming emotions tied to the loss. She is very bothered by frequent intrusive memories of her father lying dead in a hospital bed and her perception that he appeared to have been in great pain. She avoids all thoughts and reminders of his death, refusing even to say out loud that he had died for months following the death. She reports feeling constantly on guard and worried about her ability to manage without him. She jumps almost every time the phone rang for fear that she will learn that another family member had died. Joan meets diagnostic criteria for both CG and PTSD.

Finally, Matt is seeking treatment for his intense anxiety about driving; anxiety that led him to avoid being in a car at considerable and growing cost to his ability to function. Every time he is in a car, or even thinks about driving, Matt has intense physiological reactivity. In addition, vivid memories of the accident frequently intruded into his thoughts while he attempts to go about his day-to-day life. Matt has been irritable and had difficulty sleeping since the accident, reporting that he is often jumpy and quickly loses his temper. He has withdrawn from many of his friends and family and felt isolated from them. Although Matt greatly misses his wife, he feels he has been able to accept her passing and has begun to move forward in reestablishing his life with his daughters. However, those efforts have been limited by his inability to drive. Matt meets diagnostic criteria for PTSD without CG.

As these vignettes illustrate, the relationship between the type of bereavement and the presence of the PTSD syndrome is not especially straightforward. Deborah experienced a traumatic event by any conceivable definition of the word, yet does not meet diagnostic criteria for PTSD after the shooting death of her son. Joan meets full diagnostic criteria for PTSD under DSM-IV criteria, but under DSM-III or DSM-5 criteria she would be excluded from the diagnosis solely by virtue of the type of loss she experienced. In other words, she would be experiencing the PTSD syndrome despite not having technically experienced a trauma according to the letter of the diagnostic criteria.

Joan's case suggests that the sudden and unexpected death of one's father to heart failure is an event capable of eliciting the PTSD syndrome; a clinical anecdote consistent with Breslau's finding that sudden and unexpected death of a loved one was the most commonly reported event by patients meeting diagnostic criteria for PTSD. Looking beyond these clinical vignettes, it is important to note that, to our knowledge, there is no evidence to suggest that some types of bereavement cannot lead to PTSD. Accordingly, there is no evidence to support categorically excluding any type of bereavement from the definition of trauma. Although certain types of loss may place individuals at greater risk than do others, this does not mean that only those losses with high conditional probability should be considered traumatic. Analogously, although assaultive violence has a higher conditional probability of provoking PTSD than does a motor vehicle accident [12], it does not follow that motor vehicle accidents should no longer qualify as a traumatic event. Indeed, if an event is capable of eliciting the PTSD syndrome, it is unclear whether there is any clinical rationale for excluding that event from the diagnostic criteria for PTSD.

Summary and Recommendations

These clinical vignettes suggest that it is not sufficient to simply infer the presence or absence of the PTSD and CG syndromes from the type of loss. One patient may have

experienced an unequivocally traumatic event and not meet criteria for PTSD while another may have experienced a loss that seems natural and within the course of “usual human experience” on the surface, but has nonetheless provoked the full PTSD syndrome. Although some losses will not technically qualify a patient for the diagnosis of PTSD based on current criteria, we would recommend to both clinicians and clinical researchers that both CG and PTSD symptoms be assessed for all instances of bereavement. For researchers, gathering these data can be used to examine the question of whether there is a privileged relationship between specific types of loss and the PTSD syndrome; a position that is implicit in DSM diagnostic criteria but that is not supported by any evidence of which we are aware and is inconsistent with our clinical experience. If the data fail to support this position, it would suggest that the DSM should refrain from restricting the types of loss that qualify one for the PTSD diagnosis. It will be of particular interest to know whether there are any patients who (a) do not meet diagnostic criteria for a traumatic event, (b) do not meet diagnostic criteria for CG, and (c) do endorse experiencing the PTSD syndrome, as this pattern of experience would suggest that some patients persistently struggling since the loss are being omitted from the diagnostic category that best fits the symptoms they are experiencing.

For clinicians, gathering these data will provide critical information about the full breadth of the patient’s experiences, informing the case conceptualization and, in turn, how best to work with that patient to alleviate bereavement-related distress. Of particular relevance will be those symptoms of PTSD that are not well captured in CG diagnostic criteria (e.g., verbal or physical aggression, self-destructive behavior, hypervigilance, exaggerated startle response, difficulty concentrating, and difficulty sleeping) and those symptoms of CG not well captured in PTSD criteria (e.g., difficulty accepting the loss, loss of meaning or purpose, lost sense of identity, and difficulty imagining the future).

Considerations for Conceptualizing and Treating CG and PTSD in the Clinic

A complete assessment of CG and PTSD is critical to formulating a case conceptualization and treatment plan because while treatments for the two disorders do overlap in many ways, there are important differences. Here, we discuss the similarities and differences among three evidence-based treatments that one might consider for a patient experiencing PTSD and/or CG: Prolonged Exposure (PE; [15]), Cognitive Processing Therapy (CPT; [16]), and Complicated Grief Therapy (CGT; [17]). We will also discuss which treatments we would choose for our case examples based on the factors we have illustrated in this chapter as helping us to conceptualize CG and PTSD in bereaved patients.

Prolonged Exposure is rooted in the emotional processing theory of PTSD, which emphasizes the importance of directly addressing the traumatic memory in order to reduce PTSD symptoms [15]. This goal is achieved in large part by exposing the patient to feared memories, thoughts, and feelings associated with the traumatic event (imaginal exposure), as well as to situations, places, and people connected to the events that the patient may be avoiding (in vivo exposure). Over repeated exposures, the patient habituates to the memory of the trauma and the cues that trigger its recollection, learning that the memory is not dangerous and that situations that cue reminders of the trauma need not be avoided.

Cognitive Processing Therapy is based on a social cognitive theory of PTSD that focuses on the content of cognitions and the role of distorted thoughts on emotions and behaviors. Although brief exposure exercises are used, the purpose of these exercises is not for habituation; rather, the patient is guided toward recognizing and changing faulty beliefs about the trauma (e.g., guilt, self-blame) and over-generalized beliefs about oneself or the world (e.g., “I can’t ever trust my judgment again,” “The world is unsafe”). Of particular relevance to PTSD arising in the context of bereavement, some

cognitive processing therapy manuals include an optional half session to address “traumatic bereavement.” Here, the authors emphasize the importance of considering the role of losses that may be associated with PTSD, for example the “sudden, unexpected, and perhaps violent death of a significant other” ([18], p. 191). Before this optional session, the patient is asked to write a statement of at least one page on “why you think this event happened to you,” and “how has it changed or strengthened your views about yourself, other people, and the world in general?” The patient reads the written statement in session, after which the therapist helps the patient identify faulty thoughts and beliefs (e.g., guilt, denial, distorted sense of power or responsibility) that may be causing the individual to be stuck in grief. Other goals of this optional session include normalizing the grief process and differentiating it from PTSD symptoms, as well as beginning to assist the patient in viewing his/her relationship with the person who died as altered but not finished.

Lastly, CGT (see Chap. 12 for further detail on CGT) draws on a range of theoretical approaches, most notably on attachment theory, as well as on cognitive behavioral approaches for PTSD, such as prolonged exposure therapy. Perhaps not surprisingly, CGT shares similarities with prolonged exposure therapy, including an “imaginal revisiting” exercise in which patients repeatedly revisit the moment at which they first learned of the loss (cf. imaginal exposure for PTSD). Similarly, patients complete “situational revisiting” in which they face grief-related situations and activities they have been avoiding because they elicit intense grief-related distress, an exercise akin to Prolonged Exposure’s in vivo exposure. These exercises are, together, referred to as loss-focused exercises and directly address the loss event itself in much the same way that Prolonged Exposure addresses trauma.

However, there are also differences between CGT and treatments for PTSD. CGT includes a significant focus on helping the patient come to terms with the continued absence of his/her deceased loved one rather than focusing only on the loss itself. In this way, CG treatment has a broader focus on

the relationship that has been lost, rather than predominately focusing on the event in which the loss occurred. Moreover, CGT places considerable focus on restoration-oriented activities that aim to restore a sense of meaning or purpose and a capacity for joy and satisfaction in life. These exercises include discussions around personal values and aspirations and engagement in activities that move one toward those values and activities. Although there may be opportunities for such conversations in the context of Prolonged Exposure or Cognitive Processing Therapy, they are more explicitly a focus of CGT and the CGT treatment protocol provides a framework in which to explain the importance of these activities and strategies for how to achieve them. Accordingly, the focus of CGT (and, thus, the tools and strategies provided by the treatment) is somewhat broader than the focus of PTSD treatments and is more tailored to experiences commonly reported in those struggling to come to terms with loss, including considerable attention to the relationship with the deceased and a restored sense of meaning or purpose in the future.

With these considerations in mind, we would provide Deborah with CGT. Although the loss she experienced was unequivocally traumatic, Deborah does not frequently experience elevated physiological arousal, fear, or feelings that the world is unsafe in response to reminders of her son's death. She meets criteria for CG and not PTSD and the primary source of her distress is not isolated to the loss event itself, but rather includes the continued absence of her son, the loss of meaning or purpose in life, and guilt around her perception that she failed as a mother. Although Prolonged Exposure and Cognitive Processing Therapy would address some of her concerns, CGT provides a better framework for addressing the full range of her experiences. In particular, CGT provides a framework for addressing the patient's difficulty accepting the ongoing absence of her son, guilt surrounding her son's death, and difficulty restoring meaning and purpose in her own life.

Conversely, we would recommend to Matt that he complete Prolonged Exposure therapy focusing on the motor vehicle accident. Although the loss of his wife was a source

of profound grief in the weeks and months following the loss, he has made considerable progress in coming to terms with the loss. He has not, however, been able to make similar progress in his efforts to return to driving and sought care specifically to address his ongoing distress around memories of the car accident, physiological and emotional reactivity to even the thought of driving, and considerable avoidance of being on the road. The imaginal and in vivo exposure entailed in Prolonged Exposure specifically address the patient's primary focus of concern and when grief-related issues do arise in treatment, they can be incorporated as part of the standard prolonged exposure treatment protocol.

Finally, we would recommend that Joan receive CGT. Given that Joan meets criteria for both CG and PTSD, this decision is less straightforward than for the other two patients. However, it is clear that a primary source of the patient's distress is around the continued absence of her father. Even for traditional symptoms of PTSD, those symptoms are often rooted as much in her father's absence as the death itself. For example, the patient's hypervigilance stems not only from a perception that terrible events can occur at any time, but also that she is unsure how she would manage such events without her father's support. Although much of the patient's distress around the loss may have been addressed in Prolonged Exposure, the shared focus in CGT on issues related to the loss itself, the relationship with the deceased, and a restoration of meaning and purpose better addresses the full breadth of the patient's symptoms.

Summary and Recommendations

These clinical vignettes illustrate the importance of building a clear understanding of the nature of our bereaved patients' symptoms. In the clinic, we recommend considering PTSD-focused therapy (i.e., Prolonged Exposure, Cognitive Processing Therapy) for those bereaved patients who are primarily

concerned with ongoing distress around memories of the death, physiological and emotional reactivity to reminders of the death, and considerable avoidance. However, when patients also experience distress and difficulty accepting the continued absence of their loved ones and a lost sense of meaning, purpose, or personal future, CGT may offer a broader toolbox for addressing both concerns around the death itself and problems moving forward in life more generally. Importantly, we know of no empirical research that can help guide this clinical decision-making. That is, while CGT, Prolonged Exposure, and Cognitive Processing Therapy have each been shown to be effective treatments, no studies have compared their efficacy in bereaved individuals, let alone examined which therapy may be most appropriate for specific subgroups of bereaved adults. Given the overlapping nature of the PTSD and CG symptoms, as well as their respective treatments, further research is needed to build a firm understanding of the most efficacious treatment options for bereaved individuals.

Conclusion

CG and PTSD are both common psychological reactions to bereavement with considerable historical and phenomenological overlap. The overlap between these disorders poses a challenge for clinicians and clinical researchers. Often our patients' experiences do not fall cleanly in the categories of trauma vs. bereavement, nor do their emotional responses fall cleanly into the categories of CG vs. PTSD. Therefore, it is important that we assess and consider symptoms of both disorders when working with bereaved individuals, allowing the primary concerns of the patient to guide the course of treatment. As CG continues to become established in our field, it is our hope that clinical researchers will do more to assess co-occurring PTSD and CG and to evaluate the effect of treatment on these conditions in order to guide clinical decision-making regarding the assessment and treatment of the conditions in bereaved adults.

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Chapter 3

Grief Reactions: A Neurobiological Approach

Mary-Frances O'Connor and Mairead H. McConnell

Introduction

Grief is a multifaceted response to loss, often (although not exclusively) following the death of a person with whom one shares a close bond. Grief is a human inevitability, arising out of our love for our family and friends. However, individuals vary considerably in how they respond to the death of a loved one. Although most people ultimately adapt with time, a small minority—about 10% of bereaved individuals [1]—continue to experience grief of an intensity that makes it difficult to function in daily life, even many years later. This lack of adaptation can increase suicidality and even medical consequences. This severe, chronic, and profound form of grief is known as complicated grief (CG) or prolonged grief disorder (PGD). Just as someone might develop complications after surgery that prevents physical healing, the terminology of “complicated” grief reflects a theory that there is something

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preventing healing and recovery from taking place. Given the significant distress, functional impairment, and negative health consequences associated with CG, this phenomenon was recently recognized in the DSM-5 as a psychological disorder meriting further study, termed “persistent complex bereavement disorder” [2]. In the following review, we will use CG to refer to all three criteria sets: CG, PGD, and persistent complex bereavement disorder (PCBD). We assume (as much of the research to date has done) that these three are basically referring to a single phenomenon. However, we will return to this definitional issue at the end of the review. In contrast, we will refer to the typical pattern of healthy adaptation seen during bereavement as non-complicated grief (non-CG). The period of time immediately following the loss, in which grief symptoms are expected to be most intense and severe, is referred to here as acute grief.

What methods might we use to understand grief, and the differences between the most common pattern of adaptation to the death of a loved one (i.e., resilience) and the lack of adaptation we see in CG? One method is to investigate the processes occurring in the brain as we go from the perception of the death event to experiencing the emotional consequences, and incorporating the event into our memories, our schemas, and our identity. Only a few studies have started to unravel this relationship between grief and neural processes.

Neurobiological measurement provides us with one lens through which to view affective processes and attempt to understand them. Emotional experiences such as grief are often assessed using self-report, behavioral observation, or behavioral tasks. These measurements often assess outcomes without clarifying the neural architecture contributing to those behaviors and symptoms (whether promoting or inhibiting). We know that there are several neural processes that can achieve the same behavioral or subjective outcome. For instance, two individuals with grief may display the same overt behavioral symptoms and report the same level of distress. One could imagine that the first person might have difficulty with information processing, making it difficult to

incorporate the death event. A second person might have difficulty with repetitive thoughts, making it difficult to concentrate on other aspects of their life. These differences may not be evident at the level of self-report or behavioral observation. Therefore, we feel it is helpful to look at the mechanisms through which grief may become “complicated,” in concert with self-reported affect and behavior. Identifying the neurobiological mechanisms implicated in the grieving process may not only provide the ability to develop and test hypotheses at the basic science level, but also identify opportunities to intervene, optimally targeted to reduce the burden of suffering and functional impairment that can follow the death of a loved one.

Although a variety of methods can be used to measure neurobiology, functional magnetic resonance imaging (fMRI) is often the method chosen for investigating neurobiological aspects of grief. fMRI measures changes in cerebral blood flow as an indirect measure of neural activity. The accuracy or detail of the image is better than other methods such as electroencephalogram (EEG), which makes fMRI advantageous for documenting activity in diverse brain regions. fMRI also allows investigators to examine how networks of brain regions interact during mental processes. Although there is not a one-to-one correspondence of neural activation to behavior or subjective experience, mental functions implicated in grief (such as memory and emotion regulation) are instantiated in different brain regions [3]. A number of these functions may act in concert to influence how people feel and act when bereaved. In addition, structural MRI can tell us about the neural scaffolding that supports the mental functions observed using fMRI.

Although emotions have been the focus of considerable work in recent decades, we know relatively little about grief, compared to emotions such as sadness or anger. CG is characterized by recurrent painful emotions, preoccupation with the death, intense yearning for the deceased, and difficulty accepting the reality of the death, among other symptoms that cause impairment in social and occupational functioning.

CG as a disorder involves a number of transdiagnostic constructs, such as avoidance, intrusive thoughts, strong physiological response to stress, and difficulties regulating emotion. Research has also shown CG to be clearly distinct from other disorders such as depression and post-traumatic stress disorder (PTSD) [4].

Three previous papers have reviewed the results of fMRI studies of grief and CG in the past decade, the earliest of which was written by O'Connor in 2005, when only one study on neuroimaging and bereavement had been published [5]. The second was written by O'Connor in 2012, reviewing a total of four studies examining neural and immunological correlates of grief [6]. The most recent review, by Silva and colleagues, found five studies in this area [7]. While the number of neuroimaging studies of grief has increased considerably since 2005, there are still relatively few experimental paradigms designed specifically to elicit and capture the multifaceted response that is grief.

Grief Elicitation

The elicitation of grief in a sterile scanner environment could be difficult—and it was for this reason that the grief elicitation paradigm was originally developed. The paradigm is a 2×2 design: photos of the deceased contrasted with photos of a stranger, and embedded into those photos, grief-related words contrasted with neutral words. This resulted in four possible conditions [8, 9]. Several variations of this task have been used. For a study of women who had recently terminated a pregnancy due to fetal malformation (compared to women who recently had a healthy baby), the task included photos of a happy baby compared to photos of an adult with a happy or neutral facial expression [10]. These three studies employed similar grief elicitation tasks, albeit with different bereaved samples. The first study included all bereaved participants [8], the second included CG and non-CG participants [9], and the third included

bereaved and non-bereaved participants [10]. The grief elicitation paradigm was designed simply to tap the neural response to the deceased loved one compared to a stranger. However, we are now aware that this “response” comprises multiple mental functions. Gündel and colleagues reported that the grief condition evoked activity in regions implicated in affect processing, mentalizing, episodic memory retrieval, processing of familiar faces, visual imagery, autonomic regulation, and modulation/coordination of these functions.

A notable similarity across the three studies is that bereaved participants exhibited activity in brain regions previously implicated in the experience of pain, including the dorsal anterior cingulate cortex (ACC), insula, and periaqueductal gray (PAG), when viewing the spouse compared to a stranger. Non-bereaved participants demonstrated greater PAG activity compared to bereaved participants [10]; however, activation did not differ between participants with and without CG when these three regions were specifically examined [9], suggesting that these regions are involved in grief more broadly, rather than being specific to CG. This research is consistent with subjective reports of grief being an especially painful experience, both emotionally and even physically. Importantly, the neural evidence suggests that this is a common phenomenon across bereaved individuals and this neural pattern does not necessarily indicate CG.

Additionally, activation of the posterior cingulate cortex (PCC) and cuneus has been evidenced in bereaved vs. non-bereaved comparisons. However, these regions were not specifically investigated in the study of CG, limiting our ability to draw conclusions with regard to the implication of these regions in this disorder. Nonetheless, given the importance of the PCC in the processing of autobiographical emotional memories and the cuneus in visual processing, they are likely important regions for the grief elicitation task. In grief, adaptation necessarily involves emotional autobiographical memories, and evidence suggests that autobiographical memories function differently in CG [11, 12].

The PCC also functions as an important hub in the default mode network (DMN). The DMN is a network of interconnected brain regions that exhibit activation during “resting state” (i.e., when the participant is instructed to rest quietly in the scanner without any particular task) and deactivation during cognitive or attentional tasks [13]. Given that much time is spent during grief in recalling autobiographical emotional memories, it makes sense that the DMN is related to self-reference [14], autobiographical memory [15], and rumination [16]. Perturbations in DMN connectivity have been thus associated with major depressive disorder [17], a condition that also involves deficits in certain of these domains.

Only one study has investigated DMN functioning in grief: Liu and colleagues examined a group of older Chinese adults who had experienced the death of their only child [18]. Bereaved participants (compared to non-bereaved) had decreased connectivity of brain hubs within the DMN. They also showed decreased connectivity in hubs of the central executive network, including the dorsolateral prefrontal cortex (DLPFC). This region plays an important role in cognitive regulation of emotion. This was especially true in those bereaved participants with negative coping styles (e.g., avoidance, alcohol use), suggesting that differential responses to grief might be linked to differences in neural functioning.

The grief elicitation paradigm was designed simply to tap the response to the deceased loved one, using the response to a stranger for comparison. However, we are now aware that this “grief response” comprises multiple mental functions. Although the original grief elicitation task was very useful in determining what general regions might be involved in this individualized emotional response, and although some of the same regions appear in multiple studies, the task is perhaps too broad to usefully tap the critical, necessary, or sufficient neural activations in the grief response, and future research could benefit from parsing the mental functions in grief (and their concomitant neural activations) to determine how they might relate to the maintenance of complicated grief, how they might predict typical adaptation over time, or might correlate with current functioning.

Emotion Regulation

People with both acute grief and CG report intrusive grief experiences, reminders of the loss that occur unbidden, and difficulty concentrating when they experience pangs of grief. Neuropsychological functioning during bereavement has been assessed, although reviewing all related studies is beyond the scope of this chapter. However, a report from the most comprehensive study (groups that included 150 with CG, 615 with non-CG, and 4700 non-bereaved) led to the following conclusions [19]. Participants with CG had lower processing speed and verbal fluency scores compared with non-bereaved and non-CG participants, and had lower Mini Mental State Examination (MMSE) scores than those with non-CG. No differences in performance on either a Stroop task or word-learning tests of immediate and delayed recall were observed between the CG and non-CG.

Cognitive difficulties during bereavement could also be related to the interaction of emotion and cognition. The emotional Stroop (eStroop) is designed to assess emotional interference and measure the extent to which the participant can disengage from the emotionally salient stimuli in order to remain focused on the task. There are several variants of the task that have been applied to bereaved populations, including stimuli that use the name of the deceased, idiographic grief-related stimuli, and categorical grief-related stimuli. In addition, participants can be asked to report on the color of the word or the number of words on the screen (i.e., the emotional counting Stroop). All versions of the eStroop, however, are designed to assess emotional interference and the extent to which the participant can disengage from the emotionally salient stimuli in order to remain focused on the task (i.e., reporting the color or number). This is measured by comparing the reaction time to grief words compared to neutral words. Slower reaction times to grief-related words indicate greater interference.

Two of the fMRI studies of grief reported to date have utilized the eStroop. The primary finding of the first study is

that the magnitude of one's attentional bias correlated with amygdala, insula, and dorsolateral prefrontal cortex (DLPFC) activity [20]. In addition, self-reported intrusiveness of grief-related thoughts correlated with ventral amygdala and rostral anterior cingulate (rACC) activation, while avoidance correlated with deactivation of dorsal amygdala and DLPFC.

The most recent study [21] employed the eStroop with a sample consisting of CG, non-CG, and non-bereaved participants. The primary finding was that participants with non-CG exhibited activity in the rostral ACC/orbitofrontal cortex, which was not observed in the non-bereaved control group. By contrast, the CG group did not show significant activation in any areas when compared to either non-CG or non-bereaved controls. Further, the CG group displayed no rACC activation even when examined alone using a region-of-interest (ROI) approach. This could be interpreted as a relative inability to recruit the regions necessary for successful completion of this emotional task in those with CG.

It is difficult to compare the two existing eStroop fMRI studies, because of the large differences between them. Methodologically important differences (e.g., pet vs. human, length of bereavement) between the studies might account for the disparate findings. Most importantly, Freed et al. [20] used reaction time as a covariate in the analyses, and thus are not just a contrast of grief and neutral stimuli (as reported in the study by Arizmendi and colleagues). The role of the amygdala in *automatic responding* to emotional stimuli may mean that this was the relevant mental function captured by this analysis, albeit in the context of grief. In the study by Freed and colleagues, the loss was more recent (average of 3 months as opposed to 3 years), and did not categorize groups by grief severity.

Three additional behavioral studies of the eStroop in bereaved samples (without a scanning component) can be found in the literature [22–24]. The fMRI study by O'Connor and colleagues is a subset of the group who participated in the behavioral study by O'Connor and Arizmendi [24], and then additionally had a neuroimaging scan. In all of the reported reaction times (both for behavioral and neuroimaging studies),

grief words have a longer reaction time than neutral words for bereaved people (whether or not they had CG). This result is interpreted such that bereaved individuals attend more to grief cues and have a harder time disengaging from them, once they have grabbed their attention. Two of the three studies comparing CG and non-CG reported that the CG group had slower reaction times to grief words than the non-CG group [22, 24]. In contrast, the study by Mancini and Bonanno found that the CG group had faster reaction times to grief words than the non-CG group [23].

Two primary differences between the studies might account for these contradictory findings. First, the study by Mancini and Bonanno [23] differed from the other studies in that they used the name of the deceased and names of other familiar people, instead of more general grief words (e.g., “funeral”). People with CG may react very differently to things that remind them of death and grief (with avoidance) as opposed to things that remind them of their loved one (with approach). High levels of both approach and avoidance in CG have been shown clinically: approach seen in spending large amounts of time with items of the deceased. Avoidance of places, people, and objects associated with the deceased can also be seen in those with CG. Second, Mancini and Bonanno used depression as a covariate in the analyses of reaction times. Although in none of the studies did participants have major depressive disorder, it is typical for those with CG to have higher levels of depressive symptoms, and therefore those symptoms may affect reaction time. Of interest, these four behavioral studies did not differ considerably in terms of age of participants, time since the loss, or type of kinship relationship.¹

¹ These variables included that the length of time after the death event varied (Freed: 3 months, Arizmendi: 3 years, Mancini: 3 years, Maccallum: 3.5 years). Participants' mean age was different (Freed: 38, Arizmendi: 72, Mancini: 45, Maccallum: 50 years). The type of loss differed (Freed: pet loss, Arizmendi: spousal loss, Mancini: spousal loss, Maccallum: first-degree family member). The target words of task differed as well (Freed: idiographic grief words, Arizmendi: idiographic grief words, Mancini: name of the deceased, Maccallum: categorical grief words).

Additional information may be gleaned from the fact that this study also used attachment insecurity (both anxious and avoidant) to predict reaction time, across all bereaved participants. This revealed that those with more anxious attachment had slower reaction times than more securely attached individuals (although only in a condition where separation was primed). We know that those with CG are more likely to have anxious attachment [25], although Mancini and Bonanno did not report the proportion of overlap between those with CG and those with anxious attachment. Nonetheless, attachment insecurity may be an interesting mechanism to further probe the relationship between CG and the emotion regulation difficulties that are tapped by the eStroop.

Structural Differences

Three studies have investigated structural differences in bereaved groups compared to controls, although as with the previous work discussed, there is wide variation in important aspects of the studies. A study by Luo and colleagues investigated bereaved parents in China, who had lost their only child during the one-child policy in that country [26]. The researchers found that bereaved parents (compared to a group of non-bereaved parents, very carefully selected so as not to have experienced other traumas) had smaller left hippocampal volumes. They also subdivided bereaved parents into those who had PTSD and those who did not. This was a useful comparison since the association between PTSD and smaller hippocampal volume is a consistent finding [27]. Interestingly, there was no difference in hippocampal volume between these two subgroups, suggesting it was bereavement, and not PTSD specifically, that was related to the smaller left hippocampus.

A population-based study by Saavedra Pérez and colleagues went a step further and compared structural volumes for those with CG ($n = 150$), those with non-CG ($n = 615$), and non-bereaved ($n = 4731$) groups [19]. Those with current

depression were excluded. In this extremely large study, white matter and gray matter volume were assessed. Differences in specific regions of brain volume were not assessed (such as hippocampus specifically), and so cannot be compared to the other two studies. As background, gray matter is primarily nerve cell bodies, and white matter is primarily the projections (axons and dendrites) from these nerve cell bodies. Less gray matter is usually associated with reduced function for the particular brain area (e.g., language, memory). White matter is usually associated with the speed with which we process information.

Those with CG had significantly less gray matter and less white matter than the non-bereaved group. But non-CG individuals' gray matter and white matter volumes did not differ from those of the non-bereaved group. This selectivity suggests that it is the grief severity, and not only the experience of bereavement, that was associated with reduced brain volume.

Finally, a study of male youths (age 16–18) compared those who experienced ongoing and multiple traumas to a matched control group [28]. This study statistically separated out events that were of a loss nature (most of which were bereavement, but also other events like unwanted relocation) and those that were other types of traumatic events (such as witnessing a crime and being beaten up/threatened). The study excluded those with moderate to severe traumatic brain injury (TBI), and also covaried for remaining mild TBI. Overall, the group with significant adverse childhood experiences (including bereavement) had reduced gray matter and cortical folding overall, notably with smaller left hippocampal volume. However, this was not specific to grief. Higher levels of grief symptoms were associated with less surface area in bilateral pars opercularis and lingual gyrus. These regions are typically associated with executive function and language processing.

Overall, these initial studies suggest that bereavement has an effect on brain structure, and particularly the hippocampus. A smaller hippocampus is usually associated with poorer

memory. This greater atrophy may be due to neuronal pruning, reduced myelination, or decreased growth factors in the brain. Failure to find differences in white matter lesions makes it unlikely that the structural differences are due to vascular damage. The cross-sectional data do not shed any light on whether the structural differences in CG are pre-existing (because reduced brain volume could prevent normal adaptation) or whether changes in brain structure are a result of poor adaptation. However, the reduced hippocampal volume in the bereaved parents (compared to non-bereaved) suggests that this reduction is caused by bereavement, as it is difficult to make the case that a smaller hippocampus causes bereavement.

Future Directions

Impact of Criteria for Complicated Grief

Earlier in this chapter, we acknowledged that the syndrome to which we refer as complicated grief has been conceptualized and categorized in several different ways for research and diagnostic purposes. CG has also been called “prolonged grief disorder,” and its most recent label, given by the DSM-5, is PCBD. While these disorders share overlapping symptoms and presentations, the criteria vary slightly for each diagnosis. This leads to different rates of prevalence among bereaved populations. CG, for instance, captures the widest range of maladaptive functioning among the three sets of criteria, while PGD captures the smallest range. This means that some individuals who meet criteria for CG would be categorized as experiencing “typical” grief within a PGD paradigm.

The multiple sets of criteria for grief-related disorders represent an attempt within the research community to truly understand and identify the aspects of grief that are maladaptive and merit treatment. Because the designation of such criteria typically depends on how health, adaptiveness, and treatment guidelines are determined, it is understandable that different researchers may arrive at different diagnostic

schemas. While important, these nosological growing pains introduce understandable challenges to the current investigation of neurobiological processes and mechanisms involved in these disorders. It is important to take this into account when considering the work presented in this review.

We must consider, for example, that although some studies do not assess or group participants with CG, lack of assessment is not equivalent to excluding participants with CG. We should assume that studies of bereavement are capturing the entire range of grief severity—from those who are adjusting well to those experiencing significant impairment. It would be unwise to assume that studies of bereavement represent only individuals with non-CG merely because CG has not been assessed or described. Caution should be taken when comparing and interpreting results of studies with varying populations and grief criteria.

It is not surprising, then, that the neurobiological picture of grief is still somewhat unclear. Compared with other psychopathologies, relatively few studies have been conducted in this area. Even fewer have addressed the individual symptoms associated with CG (e.g., yearning, rumination, emotional pain), which we believe to be important for understanding the various mechanisms and outcomes involved in grief. Given these concerns, we suggest that moving forward, grief research should address the types and severity of grief symptoms, even when the main focus is not to assess CG. Measurements such as the Inventory of Complicated Grief (ICG) allow for a clinical cut-off as well as a continuous grief severity score for each participant. This provides researchers the opportunity to evaluate neurobiological differences related to grief severity and to compare two perspectives: one in which grief operates on a continuum and one in which it is a dichotomous category.

Longitudinal Studies

One limitation of the research to date is that current studies of the neurobiology of grief use cross-sectional data to compare bereaved and non-bereaved populations, or bereaved individuals with and without impairment, at a single time

point. In contrast, grief is inherently a process that unfolds. In order to fully assess changes in functioning over time and to better understand grief trajectories, future MRI research should focus on gathering longitudinal data.

Truly prospective data would have a baseline prior to the death event, or even before the knowledge of an impending loss, to disentangle the contribution of anticipatory grief [29]. This data is understandably difficult to collect in a bereaved sample, but it would be useful to collect data as early as possible during acute bereavement, shortly after the loss, and to follow individuals for several months or even years after the loss event. This would allow researchers to determine if there are neurological or behavioral correlates that might predict grief trajectory and later functioning. Looking at changes in function over time may also inform our understanding of the cognitive and neural processes involved in grief, such as learning and habituation, and how disruption of these processes contributes to lack of adaptation.

Longitudinal studies can also help address a question that remains unanswered in the grief literature: whether those with CG and non-CG have qualitatively different experiences from the time of grief onset (or even pre-existing individual differences). The alternative to this theory is that all bereaved individuals share similar experiences during acute bereavement but CG develops later, when there is lack of adaptation to the loss after a length of time.

The implications for understanding this difference are profound. Support for either hypothesis will inform how and when we intervene in the grief process. Furthermore, if we can identify individuals early on who may be at risk for developing CG, we may be able to prevent onset, alter prognosis, and/or significantly improve quality of life and long-term outcomes for both psychological and physical well-being.

Neural Correlates of Post-Loss Growth

An idea that remains relatively unexplored in MRI research as it pertains to grief is the idea of posttraumatic growth (PTG), or in this case, “post-loss growth.” To understand this

concept, it is important to distinguish two theories regarding bereavement. One perspective is that bereavement is akin to a psychological injury, which will heal with time and will eventually allow the individual to resume their prior level of functioning. However, the learning model of bereavement provides an alternative perspective. This model states that for some, the loss experience results in learning and acquiring knowledge that allows the individual to function differently, and perhaps even better, after the loss event [5].

This learning model is related to the concept of PTG, primarily investigated in literatures on PTSD and cancer diagnosis, which refers to the psychological changes that take place following a traumatic event and result in restructuring of one's worldview and assumptions about oneself and about life [30]. These changes have been categorized in three domains, including: (1) positive evaluation of one's competence in challenging situations, (2) deepening of relationships and increased appreciation of others, and (3) an increased appreciation of life.

It is important to note that self-report measures of PTG have been criticized for being susceptible to socially desirable responses and may simply reflect the individual's attempt to cope with trauma by framing it in a positive light. This is a valid concern, even in the context of bereavement, as we expect individuals to attempt to make meaning out of the loss. However, there is evidence that PTG is a real construct, that it represents observable behavioral changes that can be corroborated by external sources, including friends and family, and that it is relevant to bereavement [31]. Furthermore, adding neuroimaging to measurement of this construct may address the methodological concerns within self-report and lead to an understanding of whether post-loss growth occurs on a neurobiological level. For example, greater capacity to face challenging situations could be strengthened by increased inhibitory control functions in DLPFC. We recommend this as an area for future research, which will ultimately contribute to a broader understanding of the wide range of responses to loss, including not only the dysfunctional end of the spectrum such as CG, but also the positive end of the spectrum in resilience and growth.

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Chapter 4

Grief Reactions in Children and Adolescents

Alexis Revet, Lauren Laifer, and Jean-Philippe Raynaud

“Give sorrow words; the grief that does not speak knits up the o-er wrought heart and bids it break.”

William Shakespeare (1564–1616) *Macbeth*, Act 4, Scene 3.

The death of a loved one is among the most common and stressful events that a child or an adolescent can experience [1–3]. Losing a loved one in childhood or adolescence is associated with psychological distress and mental health disorders, including behavioral disorders, anxiety disorders, depression, somatization disorders, and posttraumatic stress disorder (PTSD; [4]). Bereavement among youths may further impact

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longitudinal development and global levels of functioning by decreasing an adolescent's competence in work, peer relations, career planning, and educational aspirations [5]. It is estimated that 5–10% of children and adolescents experiencing the loss of a loved one will develop clinically significant psychiatric difficulties [6]. In addition, some data suggest that young exposure to suicide of a loved one, in particular that of a parent, may be associated with increased suicide risk [7, 8].

Although normative and pathological grief reactions have been studied primarily in adults, difficult and disturbed patterns of grief, often referred to as Complicated Grief (CG) or Prolonged Grief Disorder (PGD), traumatic grief, or pathological grief, have received increasing recognition in children. The inclusion of Persistent Complex Bereavement Disorder (PCBD), in the DSM-5 Task Force and Work Groups' section entitled "Conditions for Further Studies" illustrates the existing literature about, as well as the growing interest in, pathological grief among youths and adults, alike [9]. While each of these clinical entities has slightly different diagnostic criteria, we will hereafter refer to this clinical response as Complicated Grief (CG) in line with the other chapters.

This chapter presents the most recent data on the definition, epidemiology, clinical features, and comprehensive models of grief reactions in children and adolescents. Future perspectives and research are also discussed. The management and treatment approaches to grief reactions are covered in Chap. 9.

Definitions

The terms grief, mourning, and bereavement have precise and specific meanings and should not be used in place of each other.

- *Bereavement* is the state of loss. It refers to the period after a loss during which the subject experiences grief and mourning.
- *Grief* is a normative reaction to loss, which can be either physical (the death of loved one) or symbolic. It refers to the psychological components of bereavement, especially the suffering following a significant loss.

- *Mourning* is the process of adapting to a loss. It refers to the actions and manners of expressing grief. Mourning is highly influenced by sociocultural norms.
- *Anticipatory grief* is the grief reaction of a patient or a family before an expected loss. Many of the clinical features of anticipatory grief are the same as those experienced during grief.
- *Grief work* is the process a mourner must complete successfully in order to resolve his or her grief; the term was used for the first time by Erich Lindemann in 1944 [10].

How, then, can one distinguish between *grief*, a normative process, and *Complicated Grief*? When does prolonged grief following the loss of a loved one become a psychiatric disorder and not just an intense manifestation of normal grief? Several criteria and arguments have been used to try to tackle this issue: the uniqueness of complicated grief symptoms, which are distinct from those of normal grief; the intensity and the severity of complicated grief symptoms with a qualitative leap compared to normal grief; the duration of complicated grief, which is a chronic and interminable process; and the association between complicated grief and potential negative health outcomes, specifically mental disorders [11]. These points are still debated and will be discussed throughout this chapter.

History and Models

Focus on children and adolescents in grief research is recent. The question of whether or not children could experience grief was first discussed early in the second half of the twentieth century. Inspired by Spitz's results on hospitalism and anaclitic depression, Bowlby [12–14] played an important role in demonstrating that young children could, in fact, grieve when separated from their attachment figures.

Many models of grief reactions have been developed in adults; they are summarized in Table 4.1. However, there is no standard theory of normative or pathological grieving processes in children and adolescents. The influence of Freud's theories of mourning excluded childhood from the field of grief research for a long time. The main challenge in adapting

TABLE 4.1 Major stage and phase models of grief

Theorist	Stage/phase				
Lindemann (1944) [10]	Shock and disbelief		Acute mourning		Resolution
Kübler-Ross [15]	Shock and denial	Anger	Bargaining	Depression	Acceptance
Bowlby [16] and Parkes [17]	Numbness	Yearning and searching	Disorganization and despair	Reorganization	
Worden [18]	Accept reality of loss	Work through grief	Adjust to environment	Relocate deceased emotionally	
Stroebe and Schut [19]	Loss-oriented		Restoration-oriented		

these theories and models to children and adolescents is adopting a dynamic, developmental perspective. Historically, research on childhood bereavement has focused on grieving as a time-limited process constituted by a certain number of defined and compulsory stages, which vary according to the theoretical model [20]. Lindemann (1944) systematically described normal stages of grief: shock and disbelief, acute mourning, and resolution. In her 1969 book *On Death and Dying*, Elizabeth Kübler-Ross developed a 5-stage model of grief based on her work with terminally ill patients: denial, anger, bargaining, depression, and acceptance. John Bowlby, the first to conduct research on childhood grief, adopted this perspective and developed a three-phase model: yearning and searching; disorganization; and reorganization [16]. Parkes later contributed to this model by adding an initial phase: numbness. Many other authors have developed their own stage model of childhood grief, including Furman, LeShan, Worden, Stroebe, and Schut, to name a few. These models have been critiqued, as they do not account for the fact that the grieving process may not be time-limited. Instead, it has been hypothesized that different phases of the grief process may be reactivated throughout one's lifetime and that grief can take many different forms from person to person. The increasing focus on individual grief processes is more pertinent in describing the complexity and variability of the grieving process but tends to blur the lines between normative and pathological grief responses even further.

Other theoretical models have been applied to childhood bereavement research, including theories of attachment, developed by Bowlby and his followers; development; and trauma. In developmental theories, the grieving process must be understood according to a child's stage of development, with one of the main reference frameworks being Piaget's theory of cognitive development. However, a significant limitation of developmental theories is that they describe the individual grieving process with respect to more general developmental processes but do not account for individual variations [20]. Trauma theories have conceptualized the grieving process as a specific case of traumatic response;

however, recent studies have highlighted the differences between complicated grief and PTSD in bereaved children and adolescents [21].

Recently, Neimeyer et al. proposed a pathway model to complicated and uncomplicated grief, in which the meaning of the loss to the survivor plays a key role, and highlighted the link between inability to find meaning in the loss and the intensity of CG [22, 23]. Boelen et al. [24] developed a cognitive-behavioral model of grief highlighting the importance of three core processes seen as crucial in the development and the maintenance of complicated grief: poor integration of the separation with existing autobiographical knowledge, negative global beliefs and misinterpretations of grief reactions, and anxious and depressive avoidance strategies. Lastly, from an evolutionary perspective, grief can be seen as a consequence of human attachment, or the counterpart to the ability to create a strong attachment link [25, 26].

Epidemiology

There are few epidemiological studies on rates of bereavement in childhood and adolescence. Among a nationally representative sample of children and adolescents in Great Britain, 3.5% had experienced the death of a parent or sibling and 6.3% had experienced the death of a close friend [27]. However, the real figures are likely higher, given that many of the children in this study were young. Another study reported that an estimated 4% of children and adolescents in the United Kingdom have faced the death of a parent, with 77.6% of young people reporting the loss of at least one relative or close friend [28]. Similarly, in the United States, an estimated 4% of children and adolescents experience the death of a parent before the age of 18 [29]. In a sample of Dutch primary school-aged children ($N = 1770$, mean age = 10.24 years), 5% of children had experienced the sudden death or serious injury of a loved one, such as a best friend who died suddenly or a sibling who had committed suicide [1]. Recent studies confirmed these numbers in different populations [27, 30].

Clinical Features

Although there has been increasing recognition of a disorder characterized by patterns of difficult or disturbed grief, there is not yet a clear consensus on the terminology researchers and clinicians should use to identify the same pattern of emotional and behavioral disturbances (see Chap. 14). Over the years, the most commonly used terminologies for this constellation of symptoms have been complicated grief, prolonged grief disorder, pathological grief, and traumatic grief. In the latest version of the Diagnostic and Statistical Manual (DSM), the American Psychiatric Association [9] introduced Persistent Complex Bereavement Disorder (PCBD), in the section on conditions for further studies, which contains emerging measures and models that require future research, but also as a possible diagnosis as “other specified trauma and stressor-related disorder”.

In accordance with these criteria, a diagnosis of PCBD requires that a child experience the loss of someone whom they were close to. At least one of the following core symptoms must be experienced intensely by a child:

1. Yearning for the deceased.
2. Emotional suffering and sorrow.
3. Fixation on the deceased.
4. Fixation on the circumstances of the death.

In addition, at least six of the following 12 associated symptoms, which fall under one of two symptom clusters (distress related to the death or loss of social and identity reference), must also be experienced intensely by a child:

1. Difficulty accepting the loss.
2. Feeling of disbelief or numbness since the loss.
3. Difficulty to think about the deceased in a positive way.
4. Anger or negative thinking in relation with the loss.
5. Diminished sense of self.
6. Avoidance of reminders of the loss.
7. Attraction to death.
8. Inability to trust others.

9. Feeling of loneliness.
10. Feeling that life is empty and uninteresting.
11. Feeling that one's identity or role in life has partly vanished or died.
12. Difficulty pursuing interests and moving on with life.

Lastly, a diagnosis should not be made until at least 6 months have elapsed since the death; this timeframe diagnostic criterion differs from the adults' one (12 months). These symptoms must lead to significant clinical or social consequences and disturbances and must deviate from the normal and expected reactions to loss according to a bereaved child's culture, religious beliefs, and age.

While grief, mourning, and bereavement are universal human experiences, individual reactions to death may vary considerably, especially in children, and can be influenced by a multitude of factors, including personality, culture, religious beliefs, the nature of the relationship with the deceased, and the conditions of the death. Concepts of grieving style and trajectories of grief emphasize this variability [31].

Grieving styles are individual cognitive, behavioral, and affective strategies used to adapt to loss and are highly influenced by personal and cultural factors. Doughty [32] described two types of grievers: intuitive grievers, who do not express their grief and keep secret about it, and instrumental grievers, who openly share their feelings and emotions about their experience. These grieving styles are important to take into account, as difficulties may arise when an individual uses a grieving style that does not match his or her natural style [31].

To address the concept of grief trajectories in children, some authors have suggested that the mourning journey occurs concomitantly to the child's developmental journey [33]. This highlights the importance of taking developmental phases into account to understand and clinically describe grief reactions. Table 4.2 describes these developmental phases as they relate to understanding death, as well as the most frequently associated grief reactions by age. Six developmental stages are described: infants (0- to 2-year-olds), toddlers (2- to 4-year-olds), preschoolers/early elementary schoolers (4- to 6-year-olds), primary schoolers (6- to 8-year-

TABLE 4.2 Developmental phases in understanding death and grief reactions by ages

Developmental stages	Understanding of death	Possible grief reactions
Infants (0- to 2-year-olds)	No understanding of death	General distress, irritability Changes in routine (crying, eating, sleeping) Withdrawal Fear of abandonment Regression
Toddlers (2- to 4-year-olds)	Death is seen as reversible	Confusion
	No difference between death and sleep	Separation anxiety Depression, withdrawal Regression
	Magical thinking about death	Nightmares, sleeplessness Irritability, concentration problems
Preschoolers/ early elementary schoolers (4- to 6-year-olds)	Variability in the perception and the understanding of death and of its irreversibility	Guilty feeling about the death Repeated questions about the death
	Magical thinking about death	Anger, confusion, hyperactivity Sorrow Nightmares, sleeplessness Regression

(continued)

TABLE 4.2 (continued)

Developmental stages	Understanding of death	Possible grief reactions
Primary schoolers (6- to 8-year-olds)	Understanding of the irreversibility of death	Denial that death could happen to themselves
	No capacity to generalize the experience of death to other people and to themselves	Repeated questions about the death Depression, anxiety Physical symptoms Anger Isolation Fear that something may happen to his loved ones Feeling of loss of control
Middle schoolers/ preadolescents (8–12-year-olds)	Understanding of death as a natural and universal phenomenon	Death is perceived as the end of life, as a dreadful event Curiosity about death
	Progressive access to the understanding of the cause of death	Concentration problems Guilty feeling Philosophical, religious, cultural questioning about death Feeling of being different from other children and adolescents

TABLE 4.2 (continued)

Developmental stages	Understanding of death	Possible grief reactions
High schoolers/adolescents (12- to 18-year-olds)	Existential questions about death	Sadness, depression, anxiety, isolation, anger
	Clear perception of death and its implications at an individual and general level	Concentration problems, difficulties to studying
	Abstract reasoning about death	Risky behaviors (drugs, alcohol, etc.) Feeling of isolation Impact on the adolescent process (individuation, peer recognition, etc.) Desire to protect one's family

Adapted from [31, 34–36]

olds), middle schoolers/preadolescents (8- to 12-year-olds), and high schoolers/adolescents (12- to 18-year-olds). The inability to perceive and clearly understand death may lead to grief reactions in which general distress, regression, separation anxiety, or sleep disturbances are frequently encountered. In contrast, adolescents, who have a clear perception of death, will be more prone to express their suffering through existential questions, anxiety, difficulty studying, feelings of isolation, or risky behaviors.

It is important to keep in mind that the grieving process in children and adolescents is not linear and is often marked by periods of regression during which the child may begin to re-experience symptoms of grief and have recurrent memories of the deceased. Alternatively, an increased understanding of death may allow the child to attribute a different meaning to the loss in his or her personal life. Thus, it is essential to insist on thorough and careful clinical assessment of a child's difficulties and situation to clearly perceive his or her own journey of bereavement. The two following clinical vignettes (Vignette 1 and Vignette 2) illustrate various reactions and demonstrate that these reactions can include many symptoms that do not necessarily strictly belong to the grief spectrum, including, for instance, behavioral and somatic symptoms.

Vignette 1: Pauline and Frank's stories

Pauline, age 10, lost her mother 7 months ago. Her mother died from pancreatic cancer, which was diagnosed only a month and a half before her death. In the weeks following her mother's death, Pauline started to complain of various somatic symptoms, mainly headaches and abdominal pain. Her younger brother, Frank, age 4, had trouble falling asleep, started wetting his bed again, and cried so much when going to school that his father decided to stop working for a while so that he could stay at home and take care of him. Pauline yearned for her mother and worried that something might happen to her father while she was at school. Sometimes she also felt very angry with her little brother because, as she said, *"I keep explaining him that mommy is dead but he doesn't want to understand and recognize that she will never be with us again..."*

Vignette 1 emphasizes the interactions between the specific symptoms of each member of the family and highlights the fact that children's varying developmental abilities to understand the nature of death can sometimes be difficult to deal with for both the siblings and the parent. Vignette 2, on the other hand, demonstrates that behavioral symptoms and poor academic performance can hide grief reactions.

Vignette 2: Thomas' story

Thomas, age 16, was arrested by the police for smoking marijuana. His parents met with a child and adolescent psychiatrist in the following days to ask for advice. They seemed helpless and shared that they did not understand what was happening with Thomas. He was an excellent student, but several months ago his grades started falling; at home, he stayed in his room; lunch and dinner times were always difficult, as Thomas kept quiet most of the time. His father told the psychiatrist, "I think he sees some bad guys at school." During the interview, the psychiatrist also learned that Thomas lost a good friend, Pierre, about a year ago when he was crushed by a bus while skateboarding.

The psychiatrist met with Thomas 1 week later. At first, Thomas was very reluctant to speak. Little by little, Thomas began to share with his therapist; he told him that he feels alone most of the time and often has a hard time feeling like himself, especially at school where "*everybody seems alright, except me.*" He also expressed that he sometimes feels very angry and has some difficulties motivating himself and concentrating.

Diagnosis

The primary differential diagnoses of complicated grief are normal grief, depressive disorders, posttraumatic stress disorders, and separation anxiety disorder. As compared to adults, children's clinical features are often more varied, heterogeneous, and dependent on the developmental phases and sometimes have overlap with other mood or stressor-related disorders such as major depressive disorder (MDD), PTSD, or anxiety disorders, such as obsessive compulsive disorder. Nevertheless, recent studies in both adults and children have highlighted that symptoms of PCBD are distinct from those of bereavement-related MDD and PTSD, suggesting that PCBD should be addressed in the assessment and treatment of bereaved children and adolescent seeking help following their

loss [21]. Although not an official diagnosis yet, PCBD is a clinical diagnosis, and the DSM-5 criteria can be used to guide both anamnesis and clinical observation, bearing in mind that the duration criterion in children is 6 months rather than 12.

Many screening and diagnosis instruments have been developed and validated for the assessment of grief reactions in children and adolescents and are presented in Table 4.3. Some of these assessment tools were designed to assess grief in general and not specifically complicated grief, such as the *Texas Revised Inventory of Grief* [37]. There are no validated instruments for children younger than 7–8 years old, which can be linked to the heterogeneity of symptomatology in younger ages. Most of the assessment tools presented in Table 4.3 rely on self-report, which is best explained by the fact that internalizing symptoms, such as emotional imbalance, anxiety, or self-deprecation, could be more accurately reported by the child themselves. Thus, self-report tools offer a particularly valuable insight into an individual's subjective pain.

In recent years, newer tools have been developed and validated with good psychometric properties and seem promising, even if they have been adapted from adult measures and thus lack some specificities of problematic grief among children and adolescents. Some tools focusing specifically on grief, such as the *Grief Cognitions Questionnaire for Children*, have also been recently validated and could lead to a better understanding of the mechanisms underlying the grieving process throughout childhood. In younger children especially, given the heterogeneity of reactions and symptoms, measures of general psychopathology like the *Child Behavior Checklist/6–18* [42] or the *Youth Self Report* [42] measuring externalizing and internalizing symptoms and disorders may also be useful.

When assessing bereaved children, Webb [43] suggested using a three-pronged approach based on the following key factors, which facilitates the systematic evaluation of risk and protective factors of CG:

- *Individual factors*: age, gender, journey of development, medical history and prior level of functioning, ability to create strong attachment bonds

TABLE 4.3 Main instruments to assess grief reactions in children and adolescents

Instrument	Age range (years)	Duration (minutes)	Psychometric properties	Reporter
<i>Texas Revised Inventory of Grief (TRIG; [37]); preceded by Texas Inventory of Grief (TIG; [37]) and Expanded Texas Inventory of Grief (ETIG; Zisook et al.) [38]</i>	Adults, used in adolescents	5–10	Moderate to good	Self-report
<i>The Inventory of Complicated Grief for Children (ICG-C; Dyregrov et al.) [39]; based on adult ICG (Prigerson et al.) [40]</i>	8–18	N/A	Good	Self-report
<i>Complicated Grief Assessment for Children and Adolescents – Long form (CGA-CA) (CGA-C; Prigerson et al.) [40]; preceded by the ICG</i>	7–17	20–45	N/A	Self- and parent-report + interview
<i>Inventory of Prolonged Grief for Children (IPG-C) [21]</i>	8–12	N/A	Good	Self-report
<i>Inventory of Prolonged Grief for Adolescents (IPG-A) [21]</i>	13–18	N/A	Good	Self-report
<i>Inventory of Complicated Grief-Revised for Children (ICG-RC) [41]</i>	8–17	30	Good	Interview
<i>Grief Cognitions Questionnaire for Children (GCQ-C) [21]</i>	8–18	N/A	Good	Self-report

- *Death-related factors*: type of death, cause of death, child or adolescent's relationship with the deceased, implication and presence of the child to the funerals
- *Family, social, and religious and cultural factors*, which must be taken care of in the care process

Overall, the most important aspect of the assessment process is that it must associate subjective and objective evaluation through an open clinical interview and through the use of validated assessment instruments, respectively.

The National Child Traumatic Stress Network provides useful and complete information in its section on "*Childhood Traumatic Grief*," not only for mental health professionals, but also for parents and caregivers, military children and families, educators, kids, and teens: <http://www.nctsn.org/trauma-types/traumatic-grief>

Comorbidity and Complications

MDD, substance use disorders during adolescence, and PTSD, particularly when the death of a loved one is due to a traumatic event or occurred in extreme circumstances, are the most common comorbid diagnoses associated with complicated grief [9]. Some studies suggest that increased suicide risk may be associated with younger exposure to suicide of a loved one, especially in the case of parental suicide [7, 8].

The impact of bereavement in childhood concerns a range of life issues and potential negative outcomes, from psychological suffering and psychiatric disorders to socio-economic consequences such as poorer educational attainment or salary level. For instance, the death of a parent by the age of 16 is associated with lower rates of employment at the age of 30 [44]. Nevertheless, some individuals may also develop some strengths and adaptive coping mechanisms from their traumatic experience, including a positive philosophy of life and increased capacities for empathy and open-mindedness [45].

Risk Factors

There are few studies on risk factors of complicated grief in children and adolescents. A 2004 study of adolescents exposed to a peer's suicide found that complicated grief was associated with sex (more frequent in female than male), subjects' feeling that they could have done something to prevent the death, experiencing interpersonal conflict, a previous history of depression, and a family history of anxiety disorders [41]. Contrary to a 2009 study which found no significant difference in terms of prevalence of childhood CG and PTSD between violent or sudden loss and expected loss [46], a recent study of 63 parentally bereaved children reported that children who lost a caregiver due to a prolonged illness exhibited higher levels of both maladaptive grief and post-traumatic stress symptoms as compared to children who lost a caregiver due to sudden natural death [47].

Conclusion and Perspectives

Future research should focus on the longitudinal follow-up of children and adolescents on a larger scale, as well as the bereavement of different kind of relationships, to understand the different pathways and courses of grief more precisely and to examine the impact of treatment on these trajectories. Negative outcomes should also be studied in specific at-risk populations, notably among bereaved military children [48].

Given the variety of clinical manifestations of CG, ranging from typical grief symptoms like yearning and longing, to other DSM disorders like PTSD or MDD, to nonspecific symptoms such as somatic pain, behavioral issues, and oppositional behaviors, more research is needed to confirm criteria of CG and its specificity in children and adolescents and to develop new and validated diagnostic instruments. Personal and environmental factors that support resilience and coping must also be more precisely explored and described [49].

In summary, although some data suggest that certain aspects of complicated grief in adults can be transposed to children and adolescents, specificities do exist. The number of studies focusing on these specificities may be increasing, but much remains to be done, especially concerning pathopsychophysiological models of prolonged grief in children and adolescents, and its treatment [50].

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Chapter 5

Grief: From Normal to Pathological Reactions

Eric Bui

Introduction

Bereavement—the death of a loved one—is a universal experience and a marker of the human condition. Emotional and psychological reactions to bereavement have thus been described since the antiquity. Homer in his *Iliad* (circa 1260–1240 BC) described Achilles’ reaction to the death of his friend Patroclus in these terms: “*But Achilles went on grieving for his friend, whom he could not banish from his mind, and all-conquering sleep refused to visit him. He tossed to one side and the other, thinking always of his loss, of Patroclus’ manliness and spirit... of fights with the enemy and adventures on unfriendly seas. As memories crowded in on him, the warm tears poured down his cheeks.*”

Although a highly individualized process, grief—that reflects the cognitive, emotional, and behavioral responses to

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bereavement—is experienced by virtually every human being at some point in life. As grief is both a ubiquitous and a unique psychological process, health providers often find themselves in a dilemma, caught between the need to alleviate an individual’s distress and impairment, and the danger of overly “pathologizing” their grief reaction.

In this chapter, we will review how acute grief evolves, the syndrome of complicated grief, other pathological reactions to bereavement, and a few epidemiological data.

From Acute Grief Reactions to Integrated Grief

As initially described by Bowlby [1], as human beings, we form close relationships with others. Separation from an attachment figure [1] is a threat to homeostasis that triggers an alarm reaction [2] thought to be associated with the activation of both the sympathetic adrenal medullary and the hypothalamo-pituitary adrenal (HPA) systems. The death of a loved one is thus a major life stressor and is often described as one of the most distressing and painful experiences an individual will face in his and her life. Grief may be conceptualized as a stress response to the loss of an important attachment figure. Acute grief is a natural reaction to the permanent separation from a loved one and involves difficulty adjusting to the loss with persistent separation distress and refusal of the separation accompanied by efforts to be reunited with the loved one. The distress that accompanies unsuccessful efforts to reunite with the lost loved one may over time motivate individuals to create other attachment bonds and new relationships with others that can help alleviate some of the distress. Thus, to some extent, the grief reactions may contribute to the successful readjustment to life without the deceased by providing the impetus for the formation of new attachments.

During the acute grief phase, bereaved individuals exhibit frequent thoughts and preoccupations about the

deceased, feelings of yearning, and longing and searching for that person [3]. In addition, they may experience intense and persistent emotional pain and pangs of grief as well as social withdrawal and loss of interest. Finally, individuals' emotional responses are varied and often include a mix of negative emotions such as sadness, anger, anxiety, guilt, and shame, as well as positive emotions including warmth when recalling happy memories or a sense of relief, when the death occurred after a prolonged illness. It is important to note that, at times, emotions may be dysregulated, with uncontrollable, easily triggered bouts of crying, as well as fits of positive emotions.

For most bereaved individuals, as adjustment to the loss progresses, grieving thoughts and feelings change, and the acute grief evolves into a state of integrated grief [4]. There is no definitive timeframe during which this progression should occur, but current definitions of maladaptive grief responses usually include a duration of at least 6–12 months. For the purpose of diagnostic classifications, grief reactions that are present in the first 6 months after the death of a loved one should therefore be considered as part of an acute “uncomplicated” grief.

Over time, different factors can help with the progression from acute to integrated grief, including acknowledging the loss (i.e., updating the working model and redefining life goals and plans without the deceased), and integrating both the positive and painful feelings about the loss [1].

As acute grief evolves into integrated grief—a process occurring usually in fits and starts—, emotion regulation capacities are restored, the intensity and persistence of feelings of yearning, sorrow, and loneliness are decreased (and generally become time-limited, occurring at certain specific times such as anniversaries), and the capacity for joy and satisfaction is reestablished. In addition, the finality of the death is processed and acknowledged. Finally, interest in ongoing activities and in other people reappears, and life goals and plans are revised (without the deceased).

Complicated Grief

Failure to adapt after the initial stress response (i.e., failure to move from acute grief to integrated grief) has been described as complicated grief (CG), prolonged grief disorder (PGD), and more recently, persistent complex bereavement disorder (PCBD) [5]. We will assume (as the other chapters do) that these three names are basically referring to a single phenomenon of maladaptive prolonged grieving, and failure to move to a state of integrated grief after an initial phase of acute grief. While the causes of failure to achieve a state of integrated grief are multifactorial, several factors have been proposed including: difficulties with emotion regulation, negative or unhelpful cognitions (e.g., ruminations, and counterfactual thinking), maladaptive behaviors such as avoidance, and environmental factors (e.g., lack of social support, financial hardship) [3, 4, 6–9].

Different groups of researchers have proposed varying sets of diagnostic criteria to define this syndrome of persisting grief, leading to some intense scientific debate around the specific criteria to be retained [10, 11]. This lack of common language has also led to difficulty in studying this condition, with for example, differences in core symptoms leading to differences in the prevalence rates identified. Persistent Complex Bereavement Disorder (PCBD) was introduced in the DSM-5 under “*Other Specified Trauma- and Stressor-Related Disorders*” with the explicit criteria set listed under “*Conditions for Further Study*,” as an attempt to achieve a consensus in the field. Each of the different sets of diagnostic criteria requires a minimal symptom duration since the loss to (6 months for CG and PGD, and 12 months for PCBD), and the presence of significantly distressing and/or interfering levels of grief symptoms to meet the diagnosis.

Briefly, in the DSM-5, a PCBD diagnosis requires the presence of symptoms for at least 12 months following the death of a family member or friend (at least 6 months in the case of children). It also requires at least one core symptom present on most days to a clinically significant degree among the

following four: (1) persistent yearning or longing for the deceased; (2) intense sorrow and emotional pain in response to the death; (3) preoccupation with the deceased; and (4) preoccupation with the circumstances of the death. In addition, at least six associated symptoms, on most days at a clinically significant degree, across two clusters are required: reactive distress to the death (difficulty accepting the death, bitterness or anger related to the loss, excessive avoidance of reminders of the loss, maladaptive appraisals about oneself in relation to the deceased or death, disbelief, emotional numbness, difficulty with positive reminiscing about the deceased) and social/identity disruption (difficulty trusting other individuals, feelings of loneliness, confusion about one's role in life or diminished sense of one's identity, difficulty pursuing interests, desire to die in order to be with the deceased, meaninglessness). As with other DSM-5 disorders, symptoms must interfere with the person's normal routine or cause marked distress. Finally, presenting symptoms are required to be out of proportion or inconsistent with cultural, religious, or age-appropriate norms.

Recently, a clinician-rated instrument, the Structured Clinical Interview for Complicated Grief (SCI-CG) has been developed to assess all symptoms from the different diagnostic criteria sets [12]. Table 5.1 reports the list of common grief symptoms assessed by this instrument and their inclusion in the CG, PGD, and PCBD criteria sets. Chapters 6, 7, 8 further expand on the clinical features of CG/PGD/PCBD in different specific populations.

In the validation study of the SCI-CG conducted among treatment-seeking grievers who lost a loved one at least 6 months prior, *yearning and longing for the deceased* was found to be the most frequently endorsed symptom (88% of the sample), which is in line with its inclusion in all proposed diagnostic criteria sets. However, interestingly, the second most frequently endorsed symptom was *intense feelings sorrow and emotional pain* (endorsed by 86.1% of the sample). In fact, early conceptualizations of grief had emphasized the central role of emotional pain [13], and consistent with this, a

TABLE 5.1 Common symptoms of pathological grief and their inclusion in different diagnostic criteria sets

	Complicated grief	Prolonged grief disorder	Persistent complex bereavement disorder
1. Yearning/longing for the deceased	✓	✓	✓
2. Intense feelings of sorrow/emotional pain			✓
3. Thoughts/images of deceased	✓		
4. Being lost in thoughts/daydreaming about deceased			
5. Thought/worry about how/why deceased died	✓		✓
6. Trouble accepting the death	✓	✓	✓
7. Feeling shocked/stunned since the death	✓	✓	✓
8. Emotional numbness since the death	✓	✓	✓
9. Difficulty to have positive memories about deceased			✓
10. Bitterness or anger about death	✓	✓	✓
11. Guilt/self-blame about death	✓		✓
12. Worry about not managing without deceased	✓		

TABLE 5.1 (continued)

	Complicated grief	Prolonged grief disorder	Persistent complex bereavement disorder
13. Avoidance of reminders	✓	✓	✓
14. Avoidance of getting rid of deceased's possessions	✓		
15. Intense emotional reactions to reminders	✓		
16. Physical reactions to reminders	✓		
17. Visiting cemetery/time with ashes to feel close to deceased	✓		
18. Spending time with deceased belongings	✓		
19. Experiencing pain or physical symptoms deceased had	✓		
20. Hearing her/his voice, seeing him/her	✓		
21. Wish to die to join deceased	✓		✓
22. Wish to die because life not worth living	✓		
23. Difficulty trusting others without similar loss	✓	✓	✓
24. Difficulty feeling close to others	✓		✓

(continued)

TABLE 5.1 (continued)

	Complicated grief	Prolonged grief disorder	Persistent complex bereavement disorder
25. Loneliness, feeling all alone in world since death	✓		✓
26. Feeling envious of others who did not experience loss	✓		
27. Feeling life empty without purpose, without deceased	✓	✓	✓
28. Difficulty experiencing joy/satisfaction without deceased			
29. Concern/uncertainty about role in the world/identity			✓
30. Difficulty to pursue plans for future		✓	✓
31. Interference with ability to work/socialize/function	✓	✓	✓
Duration of symptoms	6 months	6 months	12 months (6 months in children)

Adapted from Bui et al. [12]

recent network analysis study identified it as the most central symptom of PCBD [14]. It was thus surprising that it was not included as a core symptom of CG nor PGD.

Since these two reactions are core elements of CG/PGD/PCBD, their persistence may contribute to obstructing the evolution from acute grief towards integrated grief. Specifically, yearning for the deceased and emotional pain

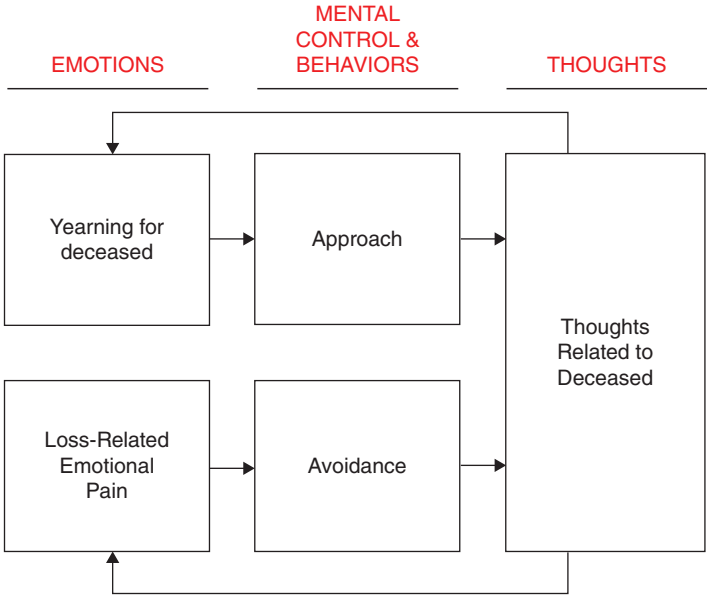


FIGURE 5.1 A Cognitive and Behavioral Model Explaining the Maintenance of Grief Reactions

can be reinforced through two feedback loops (see Fig. 5.1) [14]: (1) yearning for the deceased may trigger approach behaviors (e.g., spending time looking at pictures), that subsequently trigger thoughts related to the deceased, that in turn reinforce yearning; while (2) loss-related emotional pain (pain when thinking about the death of the loved one) may trigger avoidance behaviors, that in turn produce the opposite effect [15], increasing thoughts related to the deceased. Importantly, these two feedback loops could also reinforce each other, thus both contributing to maintaining the whole syndrome of CG/PGD/PCBD.

Other Pathological Reactions to Bereavement

In addition to the bereavement-specific maladaptive set of reactions to loss that is CG/PGD/PCBD, other psychiatric disorders might develop or be precipitated in the aftermath

TABLE 5.2 Common psychiatric disorders that can develop in the aftermath of the death of a loved one, and their main features

	Main affects	Main preoccupations	Diagnostic timeframe
CG/ PGD/ PCBD	Yearning, emotional pain	Deceased/death	≥12 months (≥6 months for children)
ASD	Fear	Life threat	≥3 days and <1 month
PTSD	Fear	Life threat	≥1 month
MDD	Sadness, anhedonia	Worthlessness/guilt	≥2 weeks

Notes: CG complicated grief, PGD prolonged grief disorder, PCBD persistent complex bereavement disorder, ASD acute stress disorder, PTSD posttraumatic stress disorder, MDD major depressive disorder

of losing a loved one. Table 5.2 reports the common psychiatric disorders that can develop in the aftermath of the death of a loved one, and their main features.

Acute Stress Disorder and Posttraumatic Stress Disorder

Acute Stress Disorder (ASD) and Posttraumatic Stress Disorder (PTSD) both occur in response to exposure to a traumatic event. DSM-5 defines traumatic events as events involving direct exposure to a life-threatening event (i.e., being a direct victim of or witnessing the trauma), as well as learning that it occurred to someone close. Learning about the death of a loved one thus qualifies as a traumatic event, and ASD and PTSD can both unsurprisingly occur after bereavement.

A diagnosis of ASD requires, in addition to the traumatic event, the presence of at least nine out of 14 symptoms of re-experiencing, dissociation, hyperarousal, or avoidance, for

at least 3 days (to a maximum of 4 weeks). A diagnosis of PTSD requires the presence of four clusters of symptoms, including: at least one symptom of re-experiencing (i.e., recurrent distressing memories of the trauma (death), recurrent distressing dreams about the trauma, flashbacks of the trauma (i.e., dissociative reactions), intense or prolonged distress to reminders, and physiological reactions to reminders); at least one symptom of avoidance (i.e., avoidance of internal or of external reminders of the trauma); at least two symptoms of negative alterations in mood and cognitions (persistent, distorted blame, persistent negative emotional state (e.g., fear, guilt, or shame), diminished interest or participation in activities, detachment from others, or inability to experience positive emotions); and at least two symptoms of hyperarousal (irritability or aggressive behavior, reckless or self-destructive behavior, exaggerated startle, hypervigilance, concentration problems, sleep disturbance), lasting at least 1 month. Few studies have specifically studied bereavement-related ASD or PTSD, and examined their relationship with CG/PGD/PCBD. Some early data suggest that CG/PGD/PCBD is highly comorbid with PTSD, with close to half of the individuals meeting diagnostic criteria for CG/PGD/PCBD also meeting current diagnostic criteria for PTSD [9]. Interestingly, a recent study identified three typologies among bereaved individuals who had lost a loved one in an airplane crash: a resilient group (without significant symptoms), a group exhibiting CG/PGD/PCBD only, and a group exhibiting both CG/PGD/PCBD and PTSD (as well as depression) [16]. These findings suggest that bereavement-related PTSD might only occur in the presence of elevated grief symptoms. Chapter 3 specifically focuses on the relationship between CG and PTSD.

As both ASD and PTSD may develop in the aftermath of the death of a loved one in a timeframe much shorter than CG/PGD/PCBD, bereaved individuals might meet diagnostic criteria for ASD or PTSD during the first few months after a loss (i.e., acute grief) even though they do not meet diagnostic criteria for CG/PGD/PCBD. Such individuals may

therefore benefit from clinical interventions for these conditions. Evidence-based treatments for PTSD include pharmacological approaches (e.g., selective serotonin reuptake inhibitor antidepressants), and trauma-focused therapies (e.g., cognitive processing therapy, prolonged exposure).

Bereavement-Related Major Depressive Disorder

From the DSM-III through the DSM-IV-TR, Major Depressive Disorder (MDD) diagnostic criteria included a bereavement exclusion criterion. This criterion ruled out the diagnosis of MDD in the first 2 months following a loss unless the bereaved individual's depressive symptoms met certain severity requirements (i.e., episode characterized by marked functional impairment, suicidality, psychosis, preoccupation with worthlessness, or psychomotor retardation) [17].

Recent studies have failed to show significant differences between bereavement-related depressive syndromes and non-bereavement-related depressive syndromes in terms of clinical characteristics and treatment response (e.g., [18, 19]). Based on these data, the bereavement exclusion was dropped from DSM-5, with the death of a loved one no longer precluding an MDD diagnosis. It has been suggested that up to a quarter of individuals with MDD might meet criteria for CG/PGD/PCBD [20], and some data suggest that about half of those with CG/PGD/PCBD might meet diagnostic criteria for MDD [9].

Briefly, in DSM-5, an individual meets MDD diagnosis if they exhibit at least five out of nine symptoms nearly every day, for 2 weeks or more. One of these symptoms must also be feeling depressed, or losing interest and/or pleasure. The other symptoms include: significant change in appetite or weight, significant change in sleep, psychomotor retardation or agitation, loss of energy or fatigue, excessive or inappropriate guilt or worthlessness, difficulty concentrating or making decisions, and recurring suicidal ideation or thoughts about death. Like ASD and PTSD, MDD may develop in the aftermath of the

death of a loved one in a timeframe much shorter than that require for CG/PGD/PCBD. As a consequence, even if a bereaved individual is still in the first few months after a loss and does not meet diagnostic criteria for CG/PGD/PCBD, they might still meet diagnostic criteria for MDD, and benefit from clinical interventions for this condition. Evidence-based treatments for MDD include pharmacological approaches (e.g., selective serotonin reuptake inhibitor antidepressants), and cognitive behavioral therapies.

Other Psychiatric Disorders

Because the loss of a loved one is a major life stressor, it is not surprising that it may be associated with increased prevalence of anxiety disorders. For example, a recent population-based study ($n = 24,534$) reported that the unexpected death of a loved one was associated with an increased first onset incidence of MDD and PTSD, as well as of panic disorder. Other empirical data also indicated that unexpected death was associated with heightened incidence of manic episodes, phobias, alcohol disorders, and generalized anxiety disorder among older adults [21]. Taken together, these data suggest that the death of a loved one is a significant vulnerability factor for the development of a range of psychiatric manifestations. In addition, similarly to other major life stressors, the death of a loved one can also precipitate relapses from pre-existing mental illnesses in remission. Even in the absence of CG/PGD/PCBD diagnosis, it is thus important to screen for other potential mood and anxiety disorders that might have been precipitated by the loss.

Epidemiology

Prevalence Rates

Although a few epidemiological studies are available, because of the different diagnostic criteria sets, it is difficult to provide

consistent and comparable prevalence rates for CG/PGD/PCBD. The diagnostic criteria sets proposed for CG thus capture a wider range of impairment, and poor functioning [11] compared to the PGD set of diagnostic criteria [10]. It is worthy to note that the ongoing debates around the validity of different diagnostic criteria sets (i.e., CG vs. PGD vs. PCBD) reflect at a larger level, the dilemma we mentioned earlier for healthcare providers: that is the tension between alleviating an individual's distress and impairment, without overly "pathologizing" a normal reaction. For that matter, this might also reflect the double roles of the DSM, to both accurately describe psychiatric disorders (and allow communication between clinicians) and serve as a reference to request reimbursement from insurance companies.

One large epidemiological study conducted in Germany ($n = 2520$) reported a prevalence of CG/PGD/PCBD in the general sample of 3.7%, and an incidence rate of 6.7% for CG/PGD/PCBD after bereavement [22]. Another study conducted in the Netherlands among $n = 5741$ older adults reported a prevalence rate of 4.8% for CG/PGD/PCBD [23]. While these figures are indicative, they might most likely evolve in the future as the field continues to refine the diagnostic criteria for CG/PGD/PCBD.

Risk Factors

Risk factors for maladjustment after the death of a loved one are interestingly not specific to one type of pathological reaction, and screening for these risk factors in practice may be helpful in identifying individuals at risk for any bereavement-related condition (e.g., CG, ASD, PTSD, or MDD). These risk factors are divided into pre-loss factors, loss-related factors, and post-loss factors. Pre-loss risk factors include prior personal or family history of psychiatric illness, female sex, and cognitive decline [22–24]. Loss-related risk factors include the type of loss (e.g., loss of a spouse or child, loss associated with stigma such as a death from suicide), the (subjectively perceived) suddenness of the loss, and the immediate

psychological response to the loss, including peritraumatic distress [25] and dissociation [26]. Finally, post-loss risk factors include negative coping strategies (e.g., avoidance, alcohol use), lack of social support, and negative consequences of the loss, such as severe financial difficulties [22, 27].

Conclusion

The experience of grief is part of the human experience and has been the object of many descriptions, some of which date back from the antiquity. Recent advances in the field have led to the increased recognition of complicated grief/prolonged grief disorder (and its differentiation from “normal grief” reactions); however, scientific debate continues regarding the specific diagnostic criteria. Despite the wealth of empirical data supporting its validity, complicated grief/prolonged grief disorder does not yet figure in the official list of DSM-5 diagnoses, and further empirical research will inform both the refinement of the diagnostic criteria and the official inclusion of this condition among the other trauma- and stressor-related disorders in future updates to the DSM-5.

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Chapter 6

Grief Reactions in the Elderly

**Gregg A. Robbins-Welty, Sarah T. Stahl,
and Charles F. Reynolds III**

Learning Objectives

1. To recognize the nature of bereavement in old age as it differs from bereavement in other stages of life, including unique social and cultural constructs.
2. To understand the relationship between grief in older adults and comorbid medical and neurologic conditions, especially psychiatric and health-related quality of life.
3. To differentiate diagnostic criteria for bereavement-related diagnoses, address the current controversy around the “over-medicalization” of grief, and review the current evidence-based practices for clinical assessment, including the Inventory for Complicated Grief (ICG) [1].

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4. To discuss the current evidence-informed treatment of bereavement-related depression and complicated grief, highlighting treatment response prediction as an area of interest and in need of further research.
5. To summarize recent research findings in neuroimaging and neurobiology that contribute to our understanding of grief reactions in older adults.
6. To address the importance of continued research into risk factors, prevention strategies for adverse grief reactions, and strategies for the facilitation of healthy adaptation to loss.
7. To briefly present what is known about other unique grief circumstances that require further bereavement research, including grief in older LGBTQ adults, suicide bereavement, and grief in the setting of palliative care and hospice medicine, and grief reactions following catastrophic natural disasters.

Key Points

1. Although a common experience, bereavement is an extremely distressing transition, especially for older adults. The majority successfully navigate this transition, but between 20 and 30% develop a mental health complication such as major depression, post-traumatic stress disorder, or Complicated Grief (CG), or substance use disorder.
2. There are well-studied social, cultural, and lifespan developmental models that describe the process by which older adults experience and adapt to loss.
3. Those experiencing complicated grief are frequently met with stigmatizing “you should be over it by now” attitudes from close family, friends, and medical professionals. This discourages the outreach for mental health services and is detrimental for coping and health outcomes.
4. A disparity exists between the need for grief services and availability/access to mental health services that provide CG treatment. Older adults experiencing CG may not know where to turn for help, often resorting to

emotional self-suppression. Those who do seek care often do so from their primary care provider or religious group.

5. The Center for Complicated Grief at the Columbia University School of Social Work (www.complicatedgrief.org) provides freely available informational resources to those suffering from and to those caring for an individual with CG [2].
6. Women are more often widowed than men, and the early transition into widowhood and successful grieving may be complicated by lack of familiarity with financial, household, and administrative tasks—such as paying bills, or cooking meals for one. Living alone is a risk factor for social isolation and poor mental health. In general, women are more likely to reach out for mental health support.
7. Older LGBTQ adults are increasingly common and have unique social and cultural considerations, especially when considering grief reactions. There are tremendous barriers limiting LGBTQs’ access to the care they need. Much more work must be done to rectify this health disparity. Access to supportive and affirmative social networks is key for promoting resiliency and successfully adapting to loss in LGBTQ older adults.
8. Older adults suffering from CG are at higher risk of early mortality. Many patients with CG die from a “broken heart.” CG is associated with serious complications, including physical and mental health exacerbations and the unmasking of early cognitive impairment.
9. CG can be effectively treated using complicated grief psychotherapy. Co-prescription of antidepressant pharmacotherapy can effectively relieve co-occurring symptoms of depression.
10. CG prevention is a small but growing field. Prevention is most efficiently accomplished by targeting older adults who exhibit risk factors for CG; these include: a history of mental health problems, heavy caregiving prior to loss, social isolation, compromised medical health, dependent attachment styles, and traumatic circumstances surrounding the death.

Introduction/Abstract

Late-life spousal bereavement is one of the most common, yet most distressing transitions faced by older adults [3]. Approximately one million people are widowed each year in the United States; nearly 75% are 65 years and older. Bereavement in older adults is unique from bereavement in younger adults because older adults are also experiencing changes in cognitive status, physical health, and quality of life, which likely complicate the grieving process.

Though most individuals adapt to the loss of a loved one and continue to live fulfilling lives, a small but significant number of older adults are at risk for developing debilitating mental health problems. Between 10 and 20% of bereaved older adults are diagnosed with major depressive disorder, anxiety, and/or prolonged, disabling grief disorder, aka, “Complicated Grief” [4–7]. Late-life mental health problems are problematic in older adults because they are prevalent and associated with physical disability, morbidity, increased health-care costs, and early mortality [8].

The aim of this chapter is to provide a comprehensive overview of bereavement in older adults, highlighting important systematic reviews, meta-analyses, and randomized controlled trials. We hope to provide clinically useful insight into the nature of bereavement in older adults as it differs from bereavement in younger adults, as well as information about assessment, treatment, prevention, and several other special topics surrounding grief in later life.

Definitions

Bereavement refers to the experience of having lost a loved one, it makes no reference to the response to such a loss [9, 10]. **Grief**, on the other hand, is one’s response to loss. Grief has many forms, and while the majority are considered normal, others are severe and pathologic in nature. Acute grief and integrated grief are separated by adaptation to the loss.

Acute Grief is the immediate response to bereavement, while **Integrated Grief** is the permanent post-mourning stage in which the finality of the loss has been accepted [10]. When adaptation does not occur, one may develop symptoms of a prolonged, impairing grief disorder, variously referred to as **Complicated Grief, Pathological Grief Disorder, or Persistent Complex Bereavement Disorder**. **Complicated Grief (CG)** is an abnormal response to the loss of a loved one. Though the exact diagnostic criteria are currently under debate, CG differs from the normal grieving process. According to Shear, CG “leaves loved ones in an immovable stage of hopelessness... Grief fills the lives of people with CG, robbing them of hope for joy or satisfaction” [2]. Considering the high prevalence of CG in older adults and its association with medical and psychiatric multimorbidities, complicated grief will be the focus of this chapter.

Bereavement in Older Adults

Experiencing the loss of a close family member, spouse/partner, or other loved-one is an unavoidable part of the aging process. Every year approximately one million people are widowed, and the vast majority is above the age of 65. Approximately 70% of older adults will experience a loss in a given 2.5 year period during late life [11]. Spousal loss is very common [12], but deaths of friends and family members (especially siblings) account for an even greater proportion of losses among older adults [10–12].

Most older adults adapt to the loss of a loved one [13]. They find ways to reshape their lives, outlook, and expectations, and continue to live prosperous lives. For some older adults, however, this normal adaptation to loss does not occur and can lead CG. Prolonged, disabling grief occurs in about 9–20% of the population [14–16], but the prevalence rate varies widely depending upon the patient’s social, cultural, and clinical background. Several surveys found that between 1 and 10% of bereaved individuals develop CG, and individuals

aged 61 or older had nearly double the rate of younger adults. Older adult women have an even higher rate [1, 17–20] compared to men. The number of adults with CG increases further to 20–23% in spousal and child bereavement, respectively [17]. In a clinical sample, a CG prevalence rate of 19% was found in hospitalized patients with unipolar depression [21], 24% in bipolar patients [22], and 31% among a mixed sample of psychiatric outpatients [23]. This higher prevalence among clinical samples highlights the association between CG and psychiatric morbidity.

Why might older adults suffer from CG at a higher rate than younger adults? One common theory relates to the ubiquitous nature of grief in older populations, which stems from a theory of ageism. Considering loss is more common in older adult populations, family members sometimes expect that the stress associated with loss would be reduced due to prior experience [24, 25]. In other words, adaptation to past losses would facilitate adaptation to later ones [26, 27]. A generally ageist society also tends to place the focus on younger nuclear family member, and the bereaved elder on the periphery. Younger family members are often viewed as those primarily bereaved when a family member is lost, while the older person is considered a secondary griever [28].

Along similar lines, there is great stigmatization for older adults experiencing grief. The Yale University Bereavement Study, a qualitative study looking at factors underlying the experience of grief in older adults, found that increased severity of grief symptoms was associated with negative reactions from friends and family members [25, 29]. Bereaved adults believed that the duration and intensity of their grief symptoms was different from what friends, family members, and even professionals expected them to be. This misunderstanding between bereaved elders and family members contributed to bereaved elders' feeling misunderstood and concerned about their grief symptoms. There appears to be a widespread societal misunderstanding of what "normal grief" means for older adults. It is frequently cited that people view older persons' normal responses to bereavement as problems

of old age including fatigue, confusion, loneliness, and social withdrawal [30]. Because they are encouraged by family and friends to put aside their grief, older adults often take on a façade of normal functioning [31]. This façade leads to less emotional coping and higher rates of grief-related complications.

The family structure and supportive function of relationships may influence the high rates of CG in older adults. As individuals age, they tend to narrow their social networks and focus primarily on emotionally rewarding relationships [32–37]. Older adults typically live within practical reach of family members [34, 36], but due to death, relocation, or family needs, meaningful relationships in later life can sometimes be less accessible. A declining birth rate and increased longevity have also resulted in families that are more vertical in structure. There are considerably more aged adults, and fewer younger family members to care for them. Plus, with increased longevity and the delay in onset of disability, caregiving duties are taken on at older age when the caregivers themselves are older and more frail [34, 37–39]. In the Yale Bereavement Study mentioned above, all participants relied on existing relationships to help with grief symptom management, but this support was usually insufficient. Most participants experienced a marked withdrawal of close friends or relatives, who dramatically reduced communication soon after the loss [25]. Though most family members tend to lack skill in discussing grief, the most common reason individuals seek professional support is at the insistence of a family member.

Lastly, among grieving older adults, there appears to be a disparity between the need for and the availability of mental health services. As with all mental health disorders, there is a well-documented and substantial gap between the number of people suffering from mental disorders and the use of mental health treatment [25, 40]. This gap is even larger in older populations when compared to younger groups [25, 41]. Low service utilization among older adults is often attributed to aspects of the U.S. healthcare system including fragmentation

of care, lack of matching of services to the preferences and needs of older adults, limited Medicare coverage for care, a shortage of providers skilled in geriatric mental healthcare, and poor continuity of services [25, 41]. The literature suggests that the gap in service use also exists, perhaps even to a higher extent, among those with a grief disorder. In a study of 110 widowed adults interviewed about 4 months after their loss, Prigerson et al. [42] found that only 33.3% of those with grief disorder symptoms had used mental health services in the previous 2 months. The Yale Bereavement Study found that participants who sought specialized mental healthcare found the process challenging and that the care received was often ineffective [25]. Because grief is a common human experience, and for most people it does lessen naturally with time, many older adults opt to do nothing and hope for self-resolution with time [25].

Clinical Point: Shear and colleagues have created a national resource designed to support families and caregivers of the elderly with grief disorders. See: www.complicatedgrief.org. This website also provides clinicians with the most recent evidence-based information and guidance for managing CG in older patients.

Grief in Older Women

As grief in older adults is distinct from grief in younger adults, it may also be experienced differently between men and women. In general, women outlive men and therefore are more likely to be widowed. An important consideration is the traditional gender socialization of women born in the 1920s–1940s. Women raised their family, while men were financial providers [43–46]. A lack of experience in managing household finances can be a significant challenge to the transition to widowhood among women [44, 47–49]. Some literature suggests that high administrative burden within the context of grief and mourning, including household maintenance [50] and financial adjustments [47,

51], are pertinent stressors and defining features of the early bereavement period for older widows [44, 52].

Living alone is a common risk factor for social isolation and poor mental health [53, 54]. About 70% of older adults living alone are women, and 46% of women over 75+ years live alone [55–57]. Financial need, poor health status, or preference to live with family are among factors that may influence a woman’s decision to cohabitate upon spousal death [43, 58]. But, others prefer to live alone to retain their independence. For many older women, this may be the first time they have ever lived alone [44, 58]. Elderly women living alone are more likely to be poor, especially with advancing age, and as many as 60% report feelings of loneliness and social isolation [55–57, 59]. In those with health problems or sensory impairments, many have difficulty complying with prescribed treatments. New or worsening symptoms often go unnoticed. Subnutrition is also often a serious concern as eating is a social activity and some elderly women who live alone do not wish to prepare full, balanced meals for one.

LGBTQ-Identified Older Adults

Complicated Grief Case Vignette: Jim

- Jim is a 72-year-old white man who identifies as homosexual. Jim is a retired salesman and has 16 years of education.
- Jim has been having a challenging time with the loss of his husband, Bill, 7 months ago. Jim and Bill were married for 5 years, but were a couple for more than three decades.
- Jim was widowed for 7 weeks prior to entering an NIMH-sponsored study at the University of Pittsburgh.
- Baseline: Moderate grief and depression:
 - Inventory of Complicated Grief (ICG) score: 11
 - Hamilton Depression score: 8
 - Clinical Global Impression Score-Severity: 6

- Unique Experiences:
 - Bill was from Texas and had significant property holdings. After his passing, legal battles ensued for Jim was not legally entitled to his husband's estate in the State of Texas. This was particularly emotionally challenging for Jim
 - Jim was very involved with his church, but had a very small social support circle, having been disowned in his 30s by his family for being homosexual
 - During their relationship, the couple had been very active in the LGBTQ group that hosted travelers in their home. Prior to Bill's passing, they had planned to host several couples as they traveled through town. Jim decided to keep those commitments, but found it difficult to be around other homosexual couples

There are 2.4 million LGBTQ adults (over 50) in the USA; this figure is expected to double by 2030. LGBTQ adults face enormous barriers to receiving formal healthcare and social support. For example, they often avoid or delay receiving formal healthcare and conceal their sexual and gender identity from health-care providers. LGBTQ adults are more likely to live alone and have financial instability, less likely to have children or stable family support, and more likely to engage in risky health behaviors (smoking, illicit drugs, excessive alcohol consumption, unprotected sexual intercourse). On top of the higher risk for physical health problems, LGBTQ older adults are also at higher risk of mental health problems, especially depressive symptoms [60].

For older adults in particular, one study found that LGBTQ seniors that were searching for retirement homes experienced unfavorable differential treatment [61]. They were offered fewer housing options at higher pricing. This further confounds the residential and financial instability frequently faced by this cohort of older adults.

Little research exists on how LGBTQ adults adapt to the loss of a loved one. One might expect that all of the aforementioned risk factors would contribute to a much higher

risk of bereavement-related complications. Access to supportive and affirmative social networks is key for the promotion of resiliency. LGBTQ older adults rely on uniquely constructed social groups (community and religious organizations) for support [61]; it is unclear how these social groups promote resilience post-loss in LGBTQ.

Complications of Bereavement in Older Adults

Given the high prevalence rates of pathological grief reactions in older adults, it is important to understand its downstream consequences. Untreated CG can last for a long time, without decrease for 10–30 years [10, 16]. While many bereaved individuals will exhibit a relative absence of grief symptoms, approximately 10–20% will evidence long-term problems in function [14–16, 20, 62]. It is important that clinicians working with older adults understand that bereavement can be associated with a number of negative outcomes, including both physical and mental health, quality of life, and mortality.

It is well known that bereavement increases the risk for mortality, especially in the first 90 days [63]. Mortality of bereavement is attributable in large part, as the old adage goes, to a “*broken heart*” [7, 64]. The increased risk of mortality is usually cited as being caused by suicide, accidents, heart disease, and/or cancer [65]. In a large primary care database in the United Kingdom, bereavement was associated with increased overall hazard of mortality, 1.25 (CI 1.21, 1.37), highest in the first 90 days [63]. Mostofsky et al. [66] documented a 21.1-fold (95% CI 13.1–34.1) increase in incidence of myocardial infarction within 24 h of learning of the death of a loved one. It is thought that these higher rates are attributable to psychological distress due to the loss, such as loneliness [65, 67, 68] and/or secondary consequences of the loss, such as changes in social ties, living arrangements, eating habits, and economic support [69, 70]. Among widowed older

adults with a grief disorder, the likelihood of suicidality is twice as high as those without [10, 71–74]. For widowers, especially, the increased risk of death is usually associated with alcohol consumption [52, 75, 76].

The physical health effects of bereavement in older adults are well documented. Clinically significant complications following the death of a loved one have been recognized since 1917, when Freud wrote *Mourning and Melancholia* [77]. Over a half century ago, Parkes et al. described the association between the first month of bereavement and a 60% increase in doctor visits [78, 79]. In another classic study, Thompson and coworkers [80] reported older two-month bereaved spouses could be 40 times as likely as non-bereaved individuals to present with a new or worsened illness. Compared to married adults, bereaved elders are more likely to experience activity-limiting pain [81, 82], nutritional problems [83], work and relationship difficulties, difficulties concentrating, decreases in meaningful social participation [24, 84], and increased physician visits with higher health-care costs [7, 85, 86]. Bereavement disorders in older adults are associated with shortness of breath, palpitations, digestive difficulties, loss of appetite, weight loss, a ten-times greater risk for hypertension and heart disease, and poor treatment adherence [6, 54, 55, 65, 74, 76–78]. CG is also associated with sleep issues, including restlessness, insomnia, and decreased sleep quality [86–89]. Poor sleep may explain why bereavement is associated with impaired neuroendocrine and immune functioning in bereaved elders [89]. This was evidenced in a study by Khanfer et al. [90], which showed that older 2-month bereaved adults, when compared to age and sex-matched non-bereaved, had lower neutrophil superoxide production when challenged with bacteria or a protein kinase activator.

CG is also associated with changes in cognitive status and affective disturbances including psychiatric comorbidities. High levels of anxiety and depression (and associated higher cortisol/dehydroepiandrosterone ratios), for example, are documented in older adults with pathological grief [5, 90]. Panic disorders/major depression, post-traumatic stress disorder, substance use disorders, anxiety, and CG not infrequently co-occur in the same individuals [91–93]. Though it

has yet to be shown whether or not it is a true risk factor, simply the experience of attachment bereavement in later life may unmask early cognitive impairment or dementia [94]. Pathological grief reactions in older adults are known to be associated with slower reaction times [95–97], deficits in the attention, concentration, and virtuospatial domains [94], impaired autobiographical memory functions [98, 99], and overall lower levels of cognitive function compared to non-bereaved individuals while controlling for age, sex, and education [5, 94, 100]. Gupta and Bonanno [101] found the ability to flexibly enhance or suppress emotional expression at will was reduced in pathological grief. Other studies have found that it is associated with impaired ability to think optimistically, attend to the needs of others, maintain plans and goals, remain calm, reduce painful emotions, and laugh [102]. Further research in the cognitive associations of pathological grief seem to suggest that those with grief disorders have overall poor cognitions about the future, greater distress, fewer goal-oriented thoughts, attentional bias towards loss-related events and memories, and a general inadequacy of emotional control [96, 98, 103–105]. Though the pathobiology of CG is still unclear, Fig. 6.1 summarizes recent research findings in neuroimaging and neurobiology that contribute to our understanding of grief reactions in older adults. Chapter 4 further reviews findings on the neurobiology of CG.

Table Citations: [95, 96, 99, 100, 105–107].

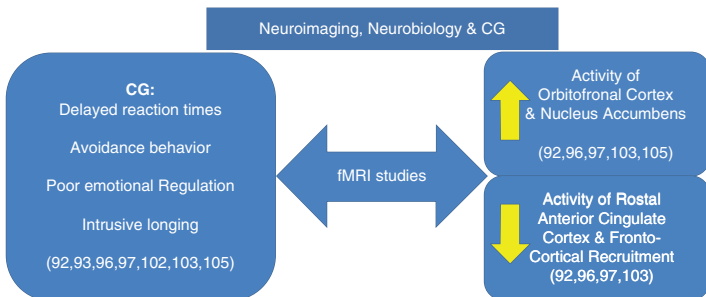


FIGURE 6.1 fMRI studies provide data correlating behavioral dimensions of complicated grief with activity in underlying neurobiological substrates

Evaluation—Clinical Presentation and Diagnosis

Clinical Suggestions—Presentation, Evaluation, and Diagnosis

We can provide clinical suggestions for the assessment and diagnosis of patients suspected of suffering from bereavement-related complications, which we will simply refer to as Complicated Grief (CG). We will start with a clinical case vignette.

Complicated Grief Case Vignette: Grace

- Grace is a 71-year-old white woman. Grace is a retired librarian and has 18 years of education.
- Complicated Grief (CG) regarding the death of her husband, John, 18 months ago. Grace and John were married for 45 years. They have four children.
- CG symptoms endorsed:
 - Frequent and intense pangs of grief
 - Thoughts of her own death and wish to never awaken
 - Intense longing
 - Feeling distant from others
 - Feeling that life is empty
 - Feeling lonely much of the time
 - Difficulty trusting others
- Baseline:
 - Inventory of Complicated Grief (ICG) score: 48
 - Quick Inventory of Depressive Symptomatology (QIDS) score: 21
 - Clinical Global Impression Score-Severity: 6
- Intervention:
 - Complicated grief therapy + citalopram/placebo (up to 60 mg/day) (HEAL trial*) [108]

- Post-treatment:
- ICG score: 8, QIDS: 10
- Grief Improvement = 2; Depression Improvement = 11
- 6-month follow-up: Stably well, continuing much improved

CG is characterized by excessive avoidance of reminders of the loss, troubling maladaptive rumination about circumstances or consequences of the death, and persistence of intense and impairing acute grief symptoms beyond what is expected according to social and cultural norms [109]. Of course, views on grief differ across cultures, and data are lacking to inform this determination. Shear describes that “*CG goes beyond the normal grieving process and leaves loved ones in an immovable stage of hopelessness*” [2]. To put it simply, could be years since the loss, but based on the patient’s response, one would think it was yesterday. The differential diagnosis of CG includes normal grief (CG is a severe grief reaction that persists for at least 12 months or 6 months in children; i.e., acute grief become chronic), depressive disorders (CG is characterized by a deep and persistent focus on the loss to the exclusion of anything else), PTSD (preoccupation with the loss and yearning for the deceased are absent in PTSD), and separation anxiety (separation from current attachment figures versus separation from a deceased individual). Delicate and thoughtful clinical judgement should be used when determining who may be suffering from CG. CG diagnosis may be difficult to diagnose in the first several months post-loss [87, 110].

The clinical interview for assessment is of critical importance. Questions about important losses should be part of a standard diagnostic evaluation, especially in the case of older patients, for whom loss is common. The presence of thoughts and behaviors that are indicative of CG should be assessed. Intense grief is not pathological; however, complicating thoughts and behaviors that impede adaptation to the loss should be identified along with grief that is excessively

intense and prolonged. Patients are sometimes ashamed of their persistently intense grief, and it is important for clinicians to ask direct questions in a sensitive and empathic way. Because comorbidities are common, the clinical evaluation of a bereaved person should also include screening for other psychiatric and medical disorders. Careful evaluation of suicidal intent and suicide plans should always be a part of the assessment. Patients should be asked about passive suicidal ideation, often exemplified by unusual risk-taking behaviors and/or the neglect of health problems [87].

A valid tool to measure CG is the Inventory of complicated grief (ICG) [1]. CG has been shown to be reliably detected by the ICG and it has been tested for people with intellectual disabilities [111] and validated in other languages [112]. Assessment by the ICG consists of reporting on 5-point scales (0 = “never,” 1 = “rarely,” 2 = “sometimes,” 3 = “often,” 4 = “always”), the frequency of 19 statements about affects, thoughts, and behaviors related to the loss of a loved one. A total score can be calculated by summing the response to all the items [113]. Scores of 30 or greater are considered to be consistent with a syndromal level of CG and warrant further evaluation and clinical intervention. The DSM5 has also recently introduced new CG symptoms (e.g., difficulty in positive reminiscing; maladaptive self-appraisals) that are not assessed by the ICG [77, 114, 115]. The ICG is a good tool for documenting the presence of symptoms and changes over time. The ICG is also useful for educating patients about their symptoms and pinpointing which ones may be the focus of intervention efforts.

Another clinically useful instrument is the Structured Clinical Interview for Complicated Grief (SCI-CG) [113]. The SCI-CG is a structured clinical interview comprising 31 symptom ratings. An optional screening section assesses characteristics related to the death, including relationship to the deceased, cause of death, and time since the death (<6 months, between 6 and 12 months, or >12 months). Each of 31 CG symptom ratings is graded on a 3-point scale (1 = “Not present,” 2 = “Unsure or equivocal,” 3 = “Present”) over the

prior month. A total score ranging from 31 to 93 is calculated by summing the scores of these items. The SCI-CG and assessment guidelines are directly available to clinicians and researchers from the website www.complicatedgrief.org.

Clinical Point: Nosology, classification and diagnostic approaches for identifying CG is a topic of ongoing and intense scientific development, needed in order to mainstream optimal diagnostic criteria.

Treatment

Goals of Treating Complicated Grief in Older Adults

Patients experiencing grief symptoms often do not seek professional treatment. When they do present for treatment, a clinician's main role is supportive. Empathy, compassion, and understanding provide a necessary foundation for clinical expertise [116]. Most individuals with CG are aware that something is wrong, but often do not know what it is. These individuals are often relieved to receive a diagnosis [10, 29], but the avoidance of misdiagnosis and overdiagnosis remains crucial to appropriate clinical management. Physicians can educate, recommend treatment options, and help patients navigate proper support channels.

Pharmacotherapy

Although antidepressants have historically been prescribed to older adults with CG [117–120], the evidence for their efficacy is unclear. Caution should be exercised in prescribing medication for CG. The best evidence available has been provided by a recent large placebo-controlled trial of citalopram for CG [116]. This trial was the first placebo-controlled randomized clinical trial to evaluate the efficacy of antidepressant pharmacotherapy, with and without complicated

grief psychotherapy, in the treatment of CG. Citalopram was found to have no efficacy beyond placebo as stand-alone treatment for CG, but suggests that adding citalopram to an effective psychotherapy regimen may alleviate co-occurring depressive symptoms. These results suggest that bereavement-related depression responds just fine to antidepressant pharmacotherapy, while CG requires tailored psychotherapy.

Psychotherapy

After several psychotherapy interventions yielded negative results when using interventions stemming from depression treatment (interpersonal therapy, for example) [121–123], researchers sought out to develop a specific psychotherapy for CG. Some success with cognitive behavioral therapy (CBT) [124] sparked the development of CBT for CG, or Complicated Grief Therapy (CGT). Chapter 13 further reviews the principles and evidence base supporting CBT and CGT for CG.

Briefly, CGT consists of reframing autobiographical narratives regarding the loss. As a form of exposure therapy, individuals are asked to gradually confront avoided aspects of the loss. The therapist challenges negative beliefs and catastrophizing misinterpretations through cognitive restructuring, helps create meaningful and positive associations, and/or helps people to set life-goals and engage in new, meaningful activities [87, 125, 126].

Numerous investigations have demonstrated the effectiveness of CGT [82, 111, 113, 122–131]. For example, CGT was tested in a large-scale RCT with elderly bereaved persons with CG, showing strong reductions in CG symptoms and beneficial effects relative to interpersonal psychotherapy (IPT) post-treatment [121, 122]. In the treatment trial that demonstrated citalopram as inefficacious comparable to placebo in the treatment of CG symptoms, CGT was found to be the treatment of choice for CG [116].

There is promising potential for the use of telemedicine for caring for patients with CG. CGT provided via the internet continues to be established and tested with promising results [128, 129, 132, 133].

It should be noted that psychotherapy has not been shown to be effective in preventing CG symptoms and prevention trials are needed [128, 134].

Predicting Treatment Response

The best CG treatments only achieve clinically meaningful improvement for roughly 70–80% of patients [114]. There is a need for treatments to be improved. It is still unclear for whom therapies yield the best results, or if specific therapies need to be developed for certain subpopulations based on pre-treatment factors or patient characteristics.

It has been shown that bereaved elders with high suicide ideation show larger reductions in CG symptoms in response to CGT than those with low suicide ideation [135]. This leads to the conclusion that patients who are in worse condition before treatment may have a better response than those who have fewer symptoms. In sum, predicting treatment response in older adults with CG is a topic of great scientific interest and where a great deal of the gaps in our knowledge lies.

Prevention of CG

Given the significant burden associated with CG, there is enormous interest in whether clinicians can encourage resilience after a significant loss through preventive efforts. In a systematic review of nine preventive interventions, researchers concluded that there was inconsistent support for their effectiveness in decreasing CG symptoms [134]. However, this finding does not mean that interventions aimed at preventing CG do not have any value. At the time the review was

conducted (2011), there were no published guidelines for CG in the DSM; therefore, studies varied in the way they defined and measured CG (which makes it hard to compare results across studies). This finding also highlights the possibility that prevention studies are more difficult to conduct among older adults. While clinicians may know who is at risk for CG after a significant loss, older adults may perceive their grief symptoms to be “normal” and may not seek help. It is very difficult to connect with older adults who are not treatment seeking.

Preventive interventions for CG can be divided into primary interventions and secondary interventions. Primary preventive interventions are those that are available to all bereaved elders, regardless of whether an intervention is needed. Examples include support group meetings and psychoeducation sponsored by counseling organizations, local churches, or senior centers. Secondary interventions are those that target people who have been identified through screening procedures as exhibiting a risk factor and therefore vulnerable to the mental health effects of bereavement. Risk factors for CG include: a history of mental health problems, heavy caregiving prior to loss, social isolation, dependent attachment style, compromised medical health, low educational attainment, and traumatic circumstances of loss, among others [5, 136].

After we screen and identify older adult who are at risk for CG, how do we intervene and facilitate adaptation to loss? In other words, what is the content of the intervention? Figure 6.2 depicts a conceptual model of the trajectory from bereavement to mental and physical health. A preventive intervention that targets known changes post-death may help promote a healthy adaptation to widowhood. For example, bereavement triggers changes in daily routines associated with physical activity, food preparation and eating, and sleep/wake regularity [137, 138]. Because physical health declines more rapidly in the later years when bereavement is most commonly experienced, bereaved elders may be especially vulnerable to the negative consequences of unhealthy lifestyle practices, such as lack of physical activity, poor

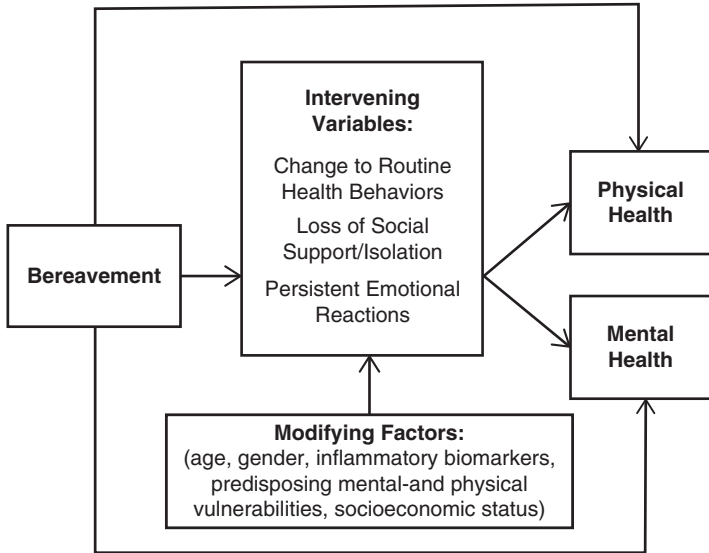


FIGURE 6.2 Proposed trajectory from bereavement to mental and physical health

nutrition, and lack of sleep. Therefore, an intervention that targets routine health behaviors may help bereaved elders reengaged with constructive activities and promote a health adaptation to widowhood. An intervention development study at the University of Pittsburgh (WELL trial) is currently testing the effects of a lifestyle intervention to promote health and welling following spousal bereavement. This intervention will test whether monitoring physical activity, healthy eating, and good sleep practices (on a tablet, daily for 12 weeks) helps adults establish a routine which in turn promotes resilience to bereavement.

Continued identification of effective prevention strategies is important for clinical practice. Whether a lifestyle intervention could prevent incident episodes of CG or clinical depression in at-risk older adults is not clear, given the limited evidence. However, the case can be made that lifestyle modification

should at least be considered a favorable option for prevention and future clinical trials are warranted. The field should also seek to understand the relative efficacy of lifestyle modification compared to other prevention strategies like increasing social engagement or psychotherapy.

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Chapter 7

Grief Reactions in the Suicide Bereaved

Alana Iglewicz, Ilanit Tal, and Sidney Zisook

Suicide bereavement is common and its effects ripple throughout society. In the United States, suicide is the 10th leading cause of death and there are approximately 120 completed suicides per day [1]. Approximately 7% of people in the United States are exposed to bereavement by suicide every year [2]. Survey results indicate that for every completed suicide, 60 people—the suicide bereaved—are intimately affected [3, 4]; countless others are affected for each suicide, albeit less intensely.

Regardless of the cause of death, grieving the loss of a loved one can be one of the most painful of life experiences. Despite the fact that every bereaved person's grief is unique, grieving the loss of a loved one to suicide adds layers of complexity to what can be an already profoundly painful

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experience. On one hand, suicide bereavement shares many features with bereavement in general: the intensity and duration of the acute grief response can range considerably; the bereaved often experience their grief in waves; and yearning, denial, anger, and sadness can be intermixed with positive recollections of the deceased. Despite these similarities, many aspects of suicide bereavement in particular add to its complexity and set it apart from bereavement in general [5]. This chapter will focus on these factors, delineating the unique context, qualitative features, sequelae, and treatment considerations for suicide bereavement.

Suicide Bereavement in the Context of Stigma

Understanding stigma is pivotal to understanding the context of suicide bereavement and suicide bereavement itself. Common definitions of stigma include a set of negative and often unfair beliefs that a society or group of people have about something or “a mark of disgrace or reproach.” Despite valiant efforts by many organizations to counter and reduce the stigma around mental illness and suicide, stigma associated with suicide remains pervasive. It is seen in insurance policies’ built-in clauses regarding suicide [6]. It is evident in the historical practices of the US government, which only recently [7] began to honorably acknowledge military families bereaved by suicide with the same presidential condolence letters sent to other families bereaved by deaths occurring in combat zones. Stigma is also apparent in the practice of certain religions which impose shameful restrictions on the grief rituals allowed for survivors of suicide loss [8]. Such religious practices rob the suicide-bereaved of the solace, comfort and guidance that religion often provides in their time of loss, perpetuating stigma, and complicating the suicide loss survivor’s grief.

Bereaved individuals typically move from the acute stages of grief to integrated grief by processing their loss [9]. However, the stigma surrounding suicide held by many members of society is often internalized by the suicide bereaved themselves,

affecting and interfering with this healing process. Stigma and resultant shame lead many suicide bereaved to feel the need to conceal the cause of death and avoid discussing the suicide lest they make others uncomfortable. Commonly, the suicide bereaved will, in turn, avoid social interactions with friends and family [10], resulting in isolation, loneliness, and the absence of those very sources of support so essential to healing after loss [8]. Simultaneously, the suicide bereaved experience more stigmatization from their friends, family, colleagues, and neighbors—their “social networks” [10]. Part of the stigmatization is overt. However, most of the stigmatization reflects a more subtle social phenomenon in which people’s lack of norms and knowledge about how to best help support someone after the death of a loved one by suicide triggers them to avoid the suicide bereaved—the concept Dyregrov has termed “social ineptitude” [11]. It is, thus, not surprising that in a review of 41 studies, the suicide bereaved experienced higher incidences of stigma, shame, and the need to conceal the cause of death from others, compared to other bereaved individuals [12]. The layers of stigma regarding suicide that exist in our society lay the foundation for suicide bereavement and pose barriers to the healing process [13].

Qualitative Features of Bereavement after Suicide

In addition to the inevitable yearning, sadness, and at times disbelief common to all grief, prominent symptoms of overwhelming guilt, confusion, shame, rejection, and anger are classic features of suicide bereavement [10, 14]. Although these qualitative features are not solely unique to suicide bereavement, they are common features of suicide bereavement, especially in aggregate. The common perception that suicide is preventable and reflects a poor decision on the behalf of the deceased provides the foundation for these qualitative features of suicide bereavement—the cascade of self-doubt, feelings of abandonment, and displaced and projected anger [5].

Self-Blame, Guilt, Confusion, and Shame

Once individuals who have lost a loved one to suicide get past the commonly experienced utter shock, confusion, and disbelief surrounding the death, most are subsequently consumed with trying to understand why their loved ones decided to end their life. Invariably, this need to understand involves holding the mirror to themselves, questioning the role that they played in the suicide. The mirror often turns into a microscope. A heightened process of self-blame may ensue [13]. The suicide bereaved micro-examine scenes from their life with the now deceased, especially those just prior to the completed suicide. These scenes are on auto-repeat, as the individual combs these memories searching for clues and warnings that they missed in real time. They are often haunted by the “*what ifs*,” the “*could haves*,” the “*should haves*,” and the “*if onlys*.” They replay past arguments and conversations, ruminate about unfulfilled plans, regret not returning calls or texts, all while trying to convince themselves that if only they had said or done something differently, their loved one would still be alive [15].

While near strangers learning of an acquaintance’s suicide death will often ask themselves, “*if only I had stopped to say hello*” or “*if only I had smiled at them as I passed them on the street*,” such ruminations are significantly more frequent and pronounced in the deceased’s inner circle—the spouse, sibling, child, or parent. Overwhelming feelings of guilt and responsibility are particularly seen in parents who lost a child to suicide [16]. The death of a child is one of, if not the most difficult loss imaginable [17], and this is even magnified when that loss is by suicide.

Thoughts of Abandonment and Rejection

Grieving individuals commonly perceive death from any cause as a form of abandonment, often unconsciously, and at times consciously. This is especially pronounced when the death is by suicide. The suicide bereaved often see the suicide

as a choice—a choice to “give up” on life, leaving loved ones behind [15]. Feelings of abandonment are particularly profound for children and spouses of individuals who died by suicide. When children lose the person to suicide whom they expect to protect them, nourish them, and comfort them, the person who brought them into this world, they understandably feel abandoned [18, 19]. Interestingly though, feelings of abandonment are less pronounced for children whose parent struggled with an alcohol use disorder prior to their completed suicide [20]. Meanwhile, considering that a marriage is typically the most intimate relationship in a person’s life, individuals whose spouse completes suicide often suffer from feelings of utter rejection and abandonment [21]. Surviving spouses are left haunted by the question of why they and their relationship with the deceased were not enough to help their loved one choose life over death [22].

Anger

It is rare for the suicide bereaved not to experience anger. The anger can be pervasive or have a direct focus. Its focus can shift with time. Common foci of the anger experienced by individuals grieving a loss by suicide include themselves, the person who died, family members, friends of the deceased, health providers, caregivers, God, and the world in general [15].

Suicide bereaved often experience anger towards the dead for leaving them, anger for not giving them a chance to help, anger for causing such heartache, shame, and rejection. At times, anger about being left to “clean up the mess” from the suicide, both literally and figuratively, can also be present. Fundamentally, aggression is part of suicide. The deceased is both the murdered and the murderer. Anger and aggression are intertwined and the surviving loved ones can experience visceral anger towards the “murderer.” There can be anger about the date of the suicide, especially when the suicide occurred on a birthday, anniversary, or celebrated holiday. The suicide will forever change the meaning of that day. Commonly, the anger morphs into guilt, as the bereaved

recognize that their loved one suffered deeply. At times, the anger is intermixed with envy and is directed towards individuals who have never suffered the loss of a loved one to suicide—individuals the bereaved perceive can and will never understand the depth of their suffering.

Sequelae of Suicide Bereavement

Partly related to the layers of guilt, shame, stigma, rejection, abandonment, and anger that characterize suicide bereavement and partly related to the same conditions that set the stage for their loved one's suicide, the suicide bereaved are at higher risk for various psychiatric comorbidities. These include Posttraumatic Stress Disorder (PTSD), Major Depressive Disorder (MDD), suicidal ideation and behaviors, and Complicated Grief (CG)—a prolonged form of grief associated with significant morbidity and mortality.

Comorbid Traumatic and Depressive Disorders

Much about suicide is traumatic. Most suicide methods involve significant bodily damage. This is most striking in regard to suicide by gunshot, but is also apparent with jumping from great heights, cutting, stabbing, hanging, suffocation, poisoning, and other suicide methods. Individuals grieving from suicide are often the first to discover the dead body, and, at times, are witnesses to the actual act of suicide. For those who witness the suicide or are the first to find the body, the haunting, consuming images of the death are often seared into their memories into perpetuity [23]. This is also the case for those who did not witness the death or body, but have to clean up after the death or live in the same residence in which the suicide occurred. Even those who did not witness the death or the body often struggle with the gruesome images created in their mind's eye after learning the details of the completed suicide. The common involvement of the police,

firefighters, and the medical examiner's office adds to the traumatic qualities of the suicide. Particularly, insensitive death notification procedures can add to the traumatic stress of the bereaved. Important efforts by the *American Foundation for Suicide Prevention* (AFSP) and the *Association for Death Education Counseling* (ADEC) have tempered the trauma associated with suicide [5], but cannot fully erase it. Suicide is inherently violent, "unnatural," and traumatic.

It is thus not surprising that individuals who lost a loved one to suicide are at higher risk of developing PTSD than are other bereaved individuals [24, 25]. Overlapping symptoms of grief and PTSD, including withdrawal, preoccupation with the death, anxiety symptoms, and hyperarousal are more common, prolonged, and intense in individuals grieving from suicide as compared to nontraumatic deaths [26].

Although the evidence is mixed, several studies have found that individuals grieving a loss to suicide are at higher risk for developing a major depressive episode (MDE) [4, 10, 12, 27, 28]. This is especially the case for people who have a pre-existing mood disorder in whom the stressors inherent to losing a loved one to suicide can trigger a major depressive episode.

Suicidal Ideation and Behaviors

Reflecting a combination of genetic and environmental factors, individuals who have a family history of suicide are at higher risk for suicide [29, 30]. Even knowing the profound layers of suffering associated with grieving a loved one's death to suicide, the suicide bereaved are at increased risk for developing suicidal ideation and behavior [31–33]. The results are quite clear and striking. In one study, knowing someone who died by suicide in the prior year was associated with a 1.6 increased risk for suicidal ideation, a 2.9 increased risk for suicidal plan, and a 3.7 increased risk for making a suicide attempt [2]. While alarming, these data also suggest powerful opportunities for primary prevention [27].

The intergenerational effects of suicide are nuanced and, at first thought, contradictory. For example, why would the people who most intimately understand the profundity of suicide's impact on loved ones choose to take their life? Several factors help explain this seeming contradiction. First, one of the clearest and most predictive risk factors for suicide is having a mental illness [34]. An exacerbation of the suicide bereaved's own mental health condition can be triggered by the suicide, putting the bereaved at risk for their own suicide. Additionally, the pain of the loss, which is interconnected with anger, perceived responsibility, rejection, and isolation, can be unbearable. For these individuals, suicide may seem like the only solution to alleviating their pain [15]. For others, the intensity of yearning for a loved one who completed suicide can lead them to kill themselves in order to reunite with their loved one in death. Similarly, killing themselves could be a way in which to feel closer to their now deceased loved one. Case reports indicate that certain people grieving the loss of a loved one to suicide will take their own lives, mimicking everything down to the details of suicide method, date, time, and/or location [15].

Complicated Grief

In the usual healing process after a loss, acute grief transforms into integrated grief, in which the grief takes up less emotional space with time and the bereaved integrates back into a meaningful life [9]. At times, as with non-suicide bereavement, CG can ensue. As indicated in the other chapters, CG, also referred to as prolonged grief disorder [35] and persistent complex bereavement disorder [36], is a bereavement reaction in which the intensity of the acute phases of grief does not abate, causing distress, interfering with functioning and leading to poor psychological and general medical health outcomes [37, 38]. The “*if onlys, could haves, and should haves*” prevail, adaptation to the loss is blocked, and healing is thwarted. Common CG symptoms

include recurring, self-blaming thoughts related to the death, anger about the death, intrusive images of the death, excessive avoidance of reminders of the loss, feelings of disbelief about the death, isolation from others, loss of meaning in life, and suicidal ideation [39–44]. These features also often characterize individuals bereaved by suicide [15] and may be magnified by the feelings of confusion, rejection, trauma, and stigma associated with suicide bereavement in particular.

Indeed, survivors of suicide loss are at high risk of developing CG [10, 11, 15, 45–49]. In one small sample of suicide-bereaved participants, Mitchell and colleagues reported CG rates of 43% [48], much higher than CG rates of 7–15% reported in the general bereaved population [50]. Further, suicide-bereaved individuals who developed CG were almost ten times more likely than those who did not develop CG to have reported suicidal ideation 1 month after the death of their loved ones, even after controlling for depression [41]. Finally, compared to other individuals with CG, some suicide-bereaved individuals with CG may have higher rates of depression, PTSD, and suicidal ideation in addition to greater impairment, isolation, and self-blame [28].

When symptoms are apparent and impairing, CG may be diagnosed as soon as 6–12 months following the death of a loved one. Some experts [51] suggest that 3–5 years is the time point at which grief after a suicide loss begins to integrate, raising the question of the applicability of the CG criteria to the “normal” timeline for grief after suicide. That said, in at least one sample studied [52], symptoms of traumatic grief 6 months after a peer suicide predicted the onset of depression or PTSD at subsequent time points. Therefore, it is important for clinicians to know how to identify CG in order to provide appropriate support and treatment when needed, especially if symptoms are impairing, however “normal” they may be. Left untreated, CG symptoms may persist indefinitely, leaving the bereaved stuck in the acute stages of their grief. But when properly managed, CG can carry an excellent prognosis [53].

Treatment Considerations

Grief is a normal and adaptive response to the loss of a loved one and the vast majority of bereaved individuals get through their grief without any need for professional intervention. Grief should not be pathologized or medicalized, regardless of cause of death. However, in light of the complexities of suicide bereavement outlined in this chapter, friends, family, colleagues, and providers should all be attuned to the importance of providing needed support. Simply stated, grief works best in the context of the love and support of others. However, the love, support and reassurance of friends, family, and, at times, spiritual leaders is often not available or sufficient for the needs of the suicide bereaved, and more help may be needed. Unfortunately, there is a paucity of treatment studies available to help guide the treatment decisions for the suicide-bereaved population [54]. Clearly, treatment must involve issues related to both separation and trauma. For many, there is a prominent role for focused support groups. For others, especially those with comorbid mental health conditions, such as major depressive disorder, posttraumatic stress disorder, and/or complicated grief, more comprehensive assessment and evidence-based treatment is warranted [55].

Support Groups

Support groups are one of the mainstays of assisting people who lost a loved one to suicide. Extant studies of support groups for the suicide bereaved indicate they are at least moderately helpful [56]. Support groups for the suicide bereaved can help participants with everything from dealing with the practicalities of life to coping with the gripping emotional wounds of suicide. For many suicide bereaved, the “check-list” of what needs to be taken care of after the death can be suffocating, especially when the items are unknown

territory. Members of support groups can help each other with tips and guidance on the pragmatic aspects of life, including handling estates, finances, and legal matters. Support groups are also a place in which participants can learn valuable ideas about how to best cope with the holidays, plan for a meaningful memorial, and speak to others who are also grieving, including children, about the suicide. It is a safe place in which participants learn from others who have done the unimaginable—setting and enacting new goals for a life that will always be marked by this tremendous, unthinkable loss.

The emotional support inherent in support groups for the suicide bereaved cannot be underestimated. Support groups are a place in which participants can feel understood, where their at times overwhelming emotions and thoughts are acceptable to share. Participation helps the bereaved normalize their experiences and simultaneously helps them feel connected to others who can fundamentally understand and relate to their struggles and pain. In essence, support groups help participants transition from feeling desperately alone in their grief to feeling connected to a caring, accepting community. Support groups also help participants find purpose by creating the circle of giving and getting, teaching and learning, supporting and being supported.

There are specific groups for whom support groups are known to be particularly helpful, including groups for children who lost a parent or other relative to suicide [55]. In fact, the more targeted (suicide bereaved versus general bereaved; parents who lost a child to suicide versus individuals who lost a loved one in general to suicide; etc.) the group is, the more therapeutic it tends to be [14]. The general consensus among experts and clinicians is that support groups are clinically useful, although more formal empirical efficacy testing may be needed. Interestingly, despite its inherent therapeutic value, few suicide bereaved seek any help, including from support group participation [57]. The reasons for this are multifactorial and warrant further study and intervention.

Treatment of Associated Mental Health Conditions

Although Section III of the handbook details the management of and treatment approaches to grief reactions, we will briefly review here specificities of suicide bereavement. Natural healing processes, even when supplemented by support groups, are not always enough. This often is the case when suicide bereavement is associated with one or more mental health condition(s). It is common for providers to rationalize that everyone who lost a loved one to suicide would be depressed or that everyone who found the body of a loved one after a completed suicide would be traumatized by that experience. Rather than being conceptualized as MDD or PTSD that might be triggered or worsened by suicide bereavement, the symptoms often are rationalized as expected under the circumstances. With suicide bereavement associated with depressive or PTSD symptoms, the fear of unnecessarily medicalizing a normal process can intervene with needed treatment. Resultantly, there is a tendency not to treat the depression or the trauma. This tendency can lead to missed opportunities for important and necessary intervention.

Before initiating treatment, one must first determine if additional mental health conditions exist, and, if so, to next refine the diagnoses. In regard to MDD, the first step is to distinguish between depressive symptoms and a major depressive episode. Sadness, grief, and sorrow are ubiquitous human experiences that should not be confused with the clinical disorder, MDD [58]. One simple way of distinguishing everyday sadness from MDD is by using the 3 “Ps”: MDD is more **persistent**, occurring most days, most of the day, for at least a few weeks; more **pervasive**, affecting not only emotions, but also the way people interact with others and think, behave, and feel about themselves; and more **pathological**, triggering ongoing distress, suffering, and impairment [59].

The next step is to remember precisely what grief and MDD represent, how to distinguish between them, and how to conceptualize their relationship. **Grief** is the normal,

expected, generally adaptive psychological, biological, interpersonal and social response to loss. **MDD**, on the other hand, is a serious, sometimes malignant, life-threatening mental disorder marked by intense, persistent and pervasive sadness and/or anhedonia. MDD generally is a recurrent condition and often is quite chronic. The death of a loved one almost always triggers grief; but, as an exquisitely stressful and sometimes traumatic life event, it may also precipitate a number of adverse health consequences, including (but not limited to) MDD.

Thus, it is helpful to rephrase the question from how to differentiate grief from MDD to the more meaningful question “how can a major depressive episode be diagnosed when it occurs in a recently bereaved person, who is still actively grieving.” And that can be a challenging clinical conundrum, even for the most experienced clinician. The DSM-5 helps clinicians understand when grief may be complicated by a co-occurring MDD. In the footnote for the diagnostic criteria of a MDD, the DSM-5 distinguishes between MDD and symptoms of grief by focusing on the differences between the key issue, the nature of dysphoria, the role of positive emotions, the content of preoccupations, self-esteem, and consolability. In ordinary grief, not complicated by a co-occurring major depressive episode, the predominant feature is a profound sense of loss, with its attendant pining and yearning for the deceased. The dysphoria in grief generally decreases in intensity over a period of weeks-months and usually occurs in waves—the so-called “pangs” of grief associated with thoughts or reminders of the deceased. The pain of grief is intertwined with positive emotions and humor, which are uncharacteristic of the pervasive dysphoria of a MDE.

Once a diagnosis is made, the next step is to determine the optimal treatment approach. There is no extant literature directly guiding us in the treatment of MDD or PTSD occurring in the context of suicide bereavement. Yet, there is no literature indicating that standard treatments do not apply and a few studies have suggested that standard treatments for MDD might be effective for depressive episodes occurring in

the context of bereavement [60–62]. In the only extant controlled study regarding the optimal treatment approach for individuals experiencing both grief and MDD, similarly to those with MDD without concurrent grief, grieving individuals who had a concurrent MDD did best on a combination of antidepressant medication and psychotherapy [63]. Extrapolating from these findings, the authors recommend providers follow American Psychiatric Association Treatment Guidelines [64] for the evidence-based treatment of both MDD and PTSD in individuals experiencing both suicide bereavement and these conditions. An integrative approach is recommended, with support for the suicide bereavement woven into the treatment of the comorbid mental health condition(s).

Treatment of CG

When CG occurs in the context of suicide bereavement, the psychiatric and psychological literature provides few, if any, empirically based guidelines [22, 65]. In the absence of evidence to suggest otherwise, the same treatment considerations apply to suicide-bereaved patients with CG as would apply to patients with CG bereaved by other modes of death. The first line of treatment for CG is psychotherapy. The most extensively studied treatment for CG is called Complicated Grief Therapy (CGT) [53, 66–68]. CGT is a blend of cognitive behavioral and interpersonal psychotherapies, adding elements of exposure, gestalt, and motivational interviewing (see Chap. 12). Briefly, its objectives are to identify and resolve complications of grief and to facilitate adaptation to loss. The treatment includes two key areas of focus: restoration (i.e., restoring effective functioning by generating enthusiasm and creating plans for the future) and loss (i.e., helping patients find a way to think about the death that does not evoke intense feelings of anger, guilt, or anxiety) [69]. While CGT is a manualized therapy, it can be administered with flexibility to address client's individualized manifestations of CG. These include the recurrent themes of

suicide bereavement: the quest to understand why, guilt, rejection, shame, anger, and stigma. When CGT is not an available treatment option, the use of cognitive behavioral therapy (CBT) [70, 71] and time-limited interpretive group therapy [72, 73] may also be effective, as can other compassionately delivered therapies that contain strategies to reduce avoidance of thoughts about the death and avoidance of activities and places that are reminders of the loss [69].

Pharmacological approaches to grief reactions and CG are detailed in Chap. 13, but briefly, despite preliminary studies suggesting promise for the efficacy of antidepressants bupropion [74] and escitalopram [61, 62], for alleviating symptoms of intense grief in bereaved individuals, a large, multi-site randomized, double-blind clinical trial [53] failed to show that antidepressants—in this case citalopram—either alone or in combination with CGT, relieve CG symptoms. However, the results indicated that there may be a role for antidepressants in reducing depressive symptoms among patients also receiving CGT. The results also suggested that when formal therapy is not an option, supportive, CG-informed clinical management, with or without medications, may help. The components of CG-informed clinical management of the suicide bereaved include: obtaining a thorough history of the relationship to the deceased, the death, and the aftermath; explaining and monitoring complicated grief symptoms; providing empathic support; and gently encouraging reengagement in daily activities.

Treatment of CG with Co-occurring MDD and/or PTSD

Many suicide bereaved with CG also meet full criteria for MDD and/or PTSD and some may have active and compelling suicidal ideation. Such situations lead to challenging clinical questions: Can the conditions be safely and effectively treated simultaneously? Does the MDD and/or PTSD need to be stabilized before CGT can be safely provided? Is it safe to

begin the exposure component of CGT in someone who is actively suicidal? Unfortunately, there are no universally accepted answers to these important questions. Each person needs to be evaluated and treatment decisions individualized based on a person's unique history, vulnerabilities, internal and external resources, support systems, and wishes.

Conclusions

Suicide bereavement is common, can be life-altering, and has both societal and intergenerational implications and effects. Suicide bereavement often is characterized by prominent symptoms of overwhelming guilt, confusion, shame, rejection, and anger. The experience of suicide bereavement is more often than not steeped in the context of stigma. In light of the stigma and the resultant isolation, loneliness, and alienation experienced by many individuals who lost a loved one to suicide, typical support from family, friends, and even clergy may not be enough. Thus, support groups can be very helpful. The layers of emotional support inherent in focused support groups for the suicide bereaved should not be underestimated. However, there are times when support groups are not sufficient. This is the case when suicide bereavement co-occurs with other mental health conditions. Whenever suicide bereavement co-occurs with other mental health conditions, including MDD, PTSD, and complicated grief, formalized assessment and treatment is warranted and can be life sustaining.

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Chapter 8

Finding Meaning in Loss: A Narrative Constructivist Contribution

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As *homo-narrans* we organically seek to make meaning of our lives in storied terms [1]. That is, we continually strive to construct coherent narratives that capture and convey our sense of identity, connection, and purpose, allowing us to create a sense of continuity and predictability in a world that frequently challenges our anticipations and beliefs, and sometimes profoundly invalidates our most cherished assumptions [2–4]. The loss of a significant person represents one such transitional moment that frequently gives rise to significant levels of anxiety and a sense of discontinuity. Like pages abruptly ripped from a book, disrupting its storyline, the loss of a loved one may create a sense of disconnection, sometimes

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contradicting pivotal elements of the survivor's self-narrative [5, 6].

It is important to acknowledge, however, that the experience of loss does not necessarily disorganize survivors' self-narratives in a way that gives rise to a search for meaning in its aftermath. Indeed, survivors of most losses are able to maintain or reconnect with a previously meaningful self-narrative and find support in it—the loss, while sad, “makes sense” in the larger scheme of their lives, in a way that does not undermine the central plot structure or themes of their self-narratives [6, 7]. This is particularly true for individuals who present a normative grief reaction following the expected losses that life presents [8], such as the death of a parent or grandparent from life-limiting illness late in life. Research supports the premise that most people bereaved by the death of spouses and even children are successful at reorganizing their personal meaning systems, accommodating the event of death within a flexible and coherent self-narrative and responding adaptively despite their grief [8–11]. This underscores the reality of resilience or recovery after some months of active grieving for most bereaved persons, who return to their baseline functioning without the assistance of professional therapists [12, 13].

Other mourners, however, encounter severe obstacles as they struggle to integrate the reality of the loss and its pervasive implications into the story of their lives. Violent death including homicide, suicide or fatal accidents [14, 15] as well as premature or untimely loss, such as the death of a child or young person [10], are associated with more severe grief reactions, prompting a relentless sense of ambiguity, disbelief, and discontinuity, as the survivor agonizingly revisits the traumatic images of the death in an attempt to make sense of it [16]. Likewise, mourners who struggle with an insecure style of attachment [17] or who are highly dependent on a partner [18] are especially prone to complicated, prolonged grief reactions. With a protracted incapacity to find significance in the loss, survivors can feel that their previous assumptions (e.g., that the world is a safe space, that the universe is just, or that they are competent to protect those they love) have been cruelly contradicted [19], especially when these benign world assumptions are held uncertainly to begin with [20].

When mourners struggle to find significance in their loss, a growing body of evidence suggests they are prone to complicated grief (CG; [21]), also termed prolonged grief disorder (PGD; [22]). Despite some differences in diagnostic criteria set, we will assume that these two terms as well as persistent complex bereavement disorder introduced in the DSM-5 [23] refer to basically the same condition. CG/PGD is characterized by intense and persistent mental distress, which includes chronic separation distress, a diminished sense of self, and a persistent difficulty reengaging with life, feeling that it is unfulfilling, empty, and purposeless since the loss of the loved one. Numerous studies have linked inability to find sense or significance in the death of a loved one to such life-limiting, socially isolating, and health-threatening grief responses, while reaffirming or reconstructing a world of meaning following loss has been found associated with more favorable outcomes (see [24], for review). For example, meaning-making—or creating relevant meaning out of loss—has been found to decrease complicated grief symptoms, and to greatly mitigate traumatic distress after highly “central” death events—that would otherwise predict poor bereavement outcomes [25]. Furthermore, making sense of the death may function as nearly a complete mediator of the impact of traumatic losses through homicide, suicide, or fatal accident, as opposed to natural death [14, 26]. This growing evidence for the role of meaning-making in adaptation to loss suggests the relevance of meaning reconstruction strategies in grief therapy, a topic to which we will now turn.

Narrative and the Reconstruction of Meaning in Grief Therapy

Viewed in narrative terms, the reconstruction of personal narratives in the wake of loss involves two forms of narrative activity: processing the *event story* of the death and its implications for survivors’ ongoing lives, and accessing the *back story* of the relationship with the deceased to resolve unfinished business and restore a sense of secure attachment [27].

While the first offers the client the opportunity to reengage with the story of loss and re-narrate it from a more flexible and adaptive perspective, mastering its more traumatic or difficult details, the second typically entails the reaffirmation or reconstruction of a continuing bond with the loved one, moving from a physical to a symbolic and more representational connection. Several different narrative techniques can facilitate the adaptive integration of loss along the two pivotal forms of narrative processing. These include evidence-based practices of *narrative retelling* ([8], p. 76) that stimulate the client to relive the story of the loss until the hardest details and meanings can be held in a less distressing fashion [28]; or *journaling* about the loss in a way that promotes finding sense or existential benefit in the experience [29,30]. Complementing this processing of the event story, other techniques such as *correspondence with the deceased* [31] or the *life imprint* technique [32] address the unfinished business found to be associated with complicated grief [17] as well as intense yearning to reinforce secure attachment to the loved one [33]. Below we present a narrative-constructivist protocol we have been implementing and evaluating in both face-to-face [24] and videoconferencing [34] adaptations, in which these techniques are integrated to facilitate the client's narrative reconstruction and meaning-making about loss. We then conclude with a case study that illustrates its application with a young woman losing her husband to sudden natural death, and offer some closing thoughts on the further extension and evaluation of this protocol.

The Meaning in Loss Protocol

Drawing on a constructivist narrative rationale, the *Meaning in Loss* (MIL) protocol proposes a series of narrative techniques organized in sequential therapeutic phases. These techniques are aimed to promote the construction of new and more adaptive ways to make sense and integrate the experience of loss and to compassionately reconnect with the lost loved one, in symbolic and active ways [27]. The intervention, currently being implemented and evaluated in a face-to-face

group therapy [24] and in an online videoconferencing format [34], comprises 12–14 sessions organized around an articulated sequence of meaning reconstruction phases, as described below. Table 8.1 provides an overview of each module.

TABLE 8.1 Meaning in Loss Protocol for complicated grief: Session, phase, technique, and summary description

Session	Phase	Technique	Summary description
1, 2	Reopening the story	Introducing the loved one	Establishing group structures, and inviting client to introduce the therapist to the deceased, reviewing the character of the relationship during life and validating his or her special qualities, illustrating these with videos, photos, or any other symbolic object that conveys central aspects of the relationship
3	Processing the event story of the loss	Chapters of life Loss timeline	Plotting or writing the “Table of Contents” of one’s life story, including significant points of transition and loss, noting emotional response to each and symbolizing or naming different life “chapters”
4		Meaning reconstruction Interview	Sifting through account of the loss, using Entry, Experiencing, Explanation, and Elaboration Questions, adding narrative retelling emphasis when death was traumatic

(continued)

TABLE 8.1 (continued)

Session	Phase	Technique	Summary description
5		Directed journaling	Writing for at least 20 min about the sense made of the loss and unsought benefits found in it in response to prompting questions
6	Accessing the back story of the relationship	Hello again letter	Reopening the dialogue with the deceased with heartfelt letter about the relationship, prompted by questions about what client wants to share and ask
7		Letter from loved one	Writing a letter back from the loved one in response to the above correspondence, typically reaffirming love and support in moving forward with life
8		Life imprint	Exploring and sharing lasting impact of deceased on client's life and values
9	Consolidation	Virtual dream story	Writing a symbolic story about themes in one's real loss to place it in perspective and consider its implications for the future
10–12	Finalization	Ritual of finalization	Creating a symbolic ending activity or ritual (e.g., letter to the former self who started therapy) and to talk and/or write about the impact of the intervention in their lives

Phase 1: Reopening the Story

Sessions 1 and 2: Introducing the Loved one

After orienting clients to the practical issues of confidentiality and structure of the therapy protocol, the therapist honors the narrative nature of attachment [35], by encouraging them to *introduce their loved ones*, describing not only their death but also the relevant aspects of their lives. Philosophically, this invitation to flesh out and appreciate the relational story of the life of the deceased constitutes an act of resistance to the dominant cultural narrative of death as loss, expunging the existence of the person and requiring detachment or “letting go” as the only approved form of resolution of bereavement. Practically, this opening move also begins to access the broader account of a shared life as well as a synoptic story of the death, as both will provide orientation for subsequent phases of therapy. Thus, clients are invited to describe who their loved ones were as persons, as members of the family, and especially in relation to them, in a way that accentuates their unique qualities, strengths, and life experiences. Some questions that may be used to prompt this discussion include *Who was ___ to you? What did having ___ in your life mean to you? Are there particular stories that ___ would want us to know about her life? and What might ___ say he appreciated about you, and how you might deal with the challenges you are facing now?* Moving from surface to depth, the therapist encourages clients to share particularly meaningful words and scenarios reminiscent of the deceased to call forward relational connections that could mitigate the pain of the loss, a theme considerably developed in later therapy modules.

Phase 2: Processing the Event Story of the Loss

Session 3: Chapters of life; Loss Timeline

As a way of scaffolding the clients’ overall life trajectories and tracing their personal loss histories, the therapist coaches them to construct a *loss timeline* [36] that includes significant

turning points and life episodes, noting their emotional and practical response to each, and segmenting these into *chapters of their lives* with distinct titles [37]. Acknowledging previous losses that punctuate the clients' life stories and placing them in chronological order allow therapist and client to recognize their role in giving shape to the latter's self-narrative, revealing previous means of coping and biographical and relational sources of resilience. Significantly, this often prompts greater awareness of the role of ambiguous losses that are unnamed and unmourned, such as miscarriages, relational breakups, job loss, and illness, all of which can otherwise be disenfranchised and unsupported [38]. Combing through the timeline helps both members of the therapeutic dyad—therapist and client—to recognize recurrent themes (e.g., of challenge and survival, abandonment or the resurgence of hope) and to connect the clients' experiences across time to relevant family, cultural, or spiritual beliefs and resources. When clients are preoccupied with the event story of the death (especially when it was sudden or violent, as in cases of suicide or fatal accident), the therapist may implement special procedures for retelling the narrative of the death to promote greater emotion regulation and sense-making in the face of a traumatic experience [16]. Drawing on protocols developed by Rynearson and his colleagues, these involve slow-motion exposure to the most difficult details of the dying narrative, as the therapist supports the client in achieving greater mastery over the experience without relying on avoidance coping [39].

Session 4: Meaning Reconstruction Interview

Having sketched the landscape of loss(es) in the clients' lives in the previous session, the therapist is now in a position to delve into the story of the death more fully, drawing on the general structure of the meaning reconstruction interview [40]. This flexible framework suggests a sequence of *Entry*, *Experiencing*, *Explanation*, and *Elaboration* questions, with several examples of each that the therapist can adapt to the

client's needs. For example, the therapist might enter the story by encouraging clients to recall details of the loss and how they responded at that time, and how this feeling has evolved since (Entry), deepen into visualization of critical scenes and their associated embodied emotions (Exploration), progress to inquiries into the sense they made about the loss when it occurred and any philosophic or spiritual beliefs that helped them do so (Explanation), and conclude with questions about the longer-term import or lessons the loss carried for their lives or sense of self (Elaboration). Experiencing and Explanation questions are prioritized when the event story of the death is particularly preoccupying or traumatic, in keeping with a restorative retelling approach. The session concludes with directed journaling homework, which encourages further reflective writing around specific prompts to help the client consolidate sense-making and benefit finding regarding the experience [30].

Phase 3: Exploring Sources of Meaning

Session 5: Models of Grief

Having drawn forth a significant amount of emotionally significant material in the previous two sessions and the journaling that followed, this fifth session provides an opportunity for therapists and clients to sift through the memories, emotions, and themes that have emerged, and to gain further perspective on them considering various contemporary models of grief. To facilitate this, the therapist briefly describes the *Dual Process Model* of coping with its depiction of oscillating attention to the loss and restored living [41], the *Two-Track Model* of bereavement with its emphasis on both biopsychosocial symptoms of grief and the pre- and postmortem relationship with the deceased [42], and the *Shattered Assumptions* model with its description of the fracturing of implicit beliefs in justice, predictability, and control resulting from a tragic loss [43]. In each case, the therapist joins with the client in considering the applicability of the concepts to their own experience of

loss to give them greater intelligibility, and to consider what most requires therapeutic attention: mindful regulation of turbulent emotion, reflective processing the implications of the death for their belief system, active engagement with avoided experiences, reaching out to relevant others, etc. The session concludes with assigning the task of writing a “*Hello Again Letter*,” as discussed below, taking care to collaborate with the client to ensure conditions of safety and usually privacy in engaging this emotionally evocative assignment.

Phase 4: Accessing the Back Story of the Relationship with the Deceased

Session 6: Hello Again Letter

Phase 4 marks a shift from focusing predominantly on the event story of the death to concentrating on the back story of the relationship to the deceased, not only in life, but also beyond the loved one’s death. In keeping with a contemporary continuing bonds model of bereavement [44], the goal of this phase is to provide resources for helping the bereaved reconstruct, rather than relinquish their attachment to the deceased, in a form that is sustainable in the person’s physical absence. Session 6 builds on the preliminary work in session 2 involving introducing the loved one, by reviewing clients’ writing of an unsent letter to the bereaved whose goal is to say “*hello again*” rather than to say a final “*goodbye*” [45].

Many clients need no further encouragement than to write as if to the deceased to speak to the heart of their relationship, how it is for them now, and what they hope or plan for going forward, sometimes spontaneously addressing lingering concerns or regrets as well as affirming love. However, when they are uncertain how to begin, the therapist can offer any of several “conversation starters” in the form of incomplete sentences, such as *My most treasured memory of you is...*, *The one question I have wanted to ask you is...*, or *I want to keep you in my life by...* [31]. Having completed this letter between sessions 5 and 6, clients can choose to email the

letter to the therapist or simply share all or part of it in session. In either case, clients read the letter aloud in session (unless they request that their therapist, or in the case of group therapy, another trusted group member do so), to witness, validate, and explore the passionate feelings and meanings it conveys. After discussing both the content and process of this writing, the therapist suggests that clients write letters back to themselves on behalf of the loved ones, in a way that addresses the feelings, questions, and needs that their own letters implicitly or explicitly contain.

Session 7: Letter from the Loved One

Having drafted a letter as if from the loved one as a between-session assignment, clients speak about the usually vividly emotional experience of doing so, and read the letter to their therapist in session 7. Alternatively, or additionally, the therapist may also read the letter to the client with expressiveness, which can deepen the sense of the letter speaking to them with a voice outside the self. For many clients, this restoration of a symbolic dialogue with the deceased introduces further correspondence to and from their significant persons, helping install their voices as a kind of “*portable secure base*” that remains accessible despite their physical absence. To further consolidate this experience, clients are assigned the life imprint exercise as homework prior to the next session.

Session 8: The Life Imprint

In keeping with a postmodern conception of self, the meaning reconstruction approach presumes that our personalities are constructed as a *pastiche* or residue of innumerable relationships with others, and especially those who play intimate roles in our lives. Accordingly, the life imprint encourages bereaved clients to trace the impact of the deceased on their personal identities, at levels ranging from their gestures and mannerisms, through their choice of vocations and avocations, to their most abiding characteristics and values [32].

Reviewing these multiple imprints with their therapists, who encourage elaboration on the embodied or enacted legacies in the form of memories and stories, conveys the deep sense in which the deceased have a continued existence in and through the clients' own lives. Although this is typically deeply affirming of cherished bonds, occasionally imprints are ambivalent or even negative, in which case therapists collaborate with the client in discovering ways to relinquish or release them. The session can end with a plan to perform an activity that honors the imprint of the loved one, often by engaging in meaningful actions (visiting a special, but previously avoided, location), or performing a dedicated act of kindness that extends the loved one's concerns [46].

Session 9: Further connections

In this session, clients report back on their self-observations following the work on the back story of their relationship to the deceased over the last few weeks. The therapist engages clients in discussion of additional possible expressions of connection to their loved ones, as in dreams, experiences of their tangible or intangible presence in clients' daily lives, and for many of the bereaved, a sense of spiritual connection that implies the prospect of reconnection in an afterlife. Leading from one step behind, the therapist follows clients' cues in such discussions, taking care to respect their personal and cultural beliefs and practices. This session also serves as a kind of "expansion joint," permitting further attention to the correspondence with the deceased or life imprint methods for clients who choose to explore them further.

Phase 5: Consolidation

Session 10: Virtual Dream Stories

To promote integration of the work of therapy by fostering an imaginative, self-distancing perspective [47], session 10 engages clients in writing a brief "make believe" story about themes of loss for 8 min during the session, as the therapist circulates

through the room in the case of group therapy, or steps out of the room in individual therapy, or away from the camera in online videoconferencing to give clients privacy without distraction. Termed a *virtual dream story* because of its draw toward a fairy tale or magical realist fictional style, the method involves priming clients with two elements each of *setting* (e.g., a traumatic loss, an empty house), *figures with voice* (e.g., a crying child, a talking animal), and potentially *symbolic objects* or features (e.g., a mountain, a sunrise), which they are encouraged to include in any form they like into the narrative [48]. The short time available for the writing tends to circumvent the interruption of a self-critical or editorial voice, and the resulting story is typically emotionally powerful, and at this point in therapy, hopeful, whether the plot of the story literally or figuratively recapitulates the plots or themes of clients' personal loss stories. After reading aloud and discussing the resulting narrative, client and therapist can use any of several additional techniques to extend the method in healing directions (e.g., facilitating imaginal dialogues between pairs of elements, or retelling the story from the perspective of one of the elements to decenter the narration and discover in it new possible meanings). Other alternatives prompt clients to consider what the story reveals about themselves, about what they need, so that they can plan practical steps to meet these needs in the coming week [49].

Session 11: Ritual Planning

As therapy moves toward termination, the therapist coaches clients to plan a *ritual of remembrance* that honors their loved ones, or a *ritual of renewal* that symbolizes the new possibilities they wish to embrace in the future [38]. For example, clients may pursue a legacy project such as launching or contributing to a charitable cause that reflects the core values of the deceased, or plan a holiday ceremony as a family that acknowledges the deceased but also recommits the family members as a unit to their shared future in their new form. Some symbolic steps in these directions can be taken immediately, whereas others inherently represent longer-term projects to be nurtured over time.

Session 12: Ritual Reporting and Termination

In what may be the final session of the planned series, clients report on their success and next steps with their rituals of remembrance and renewal, and review turning points in their therapeutic journey toward greater hope and meaning. In individual therapy, the therapist might give the client a small symbolic gift (e.g., a stone engraved with the word “*peace*” or “*remembrance*”) that captures an important theme of the therapy, whereas in group therapy the group itself might practice a ritual to recognize their joint efforts across the past few months, as through writing a collaborative poem to which each group member contributes a single line [50]. In both cases, the action serves as a simple but memorable means of recognizing the solemnity of the life transition, commemorating the work of therapy, and anchoring shared hopes for a fulfilling future.

Additional Sessions

As many cases seen in both individual and group settings involve intervention for complicated grief for quite tragic losses such as the death of a child, early widowhood or sudden, violent death, allowance is made on an as-needed basis for an additional two sessions to provide further support and consolidation of therapeutic gains. Of course, when used as a flexible framework for therapy outside the protocol of a controlled evaluation such as that which is currently underway [34], therapists can adopt further modifications to the flow or focus of modules to tailor them to the specific needs of a client or group. For example, incorporation of more trauma-informed methods for engaging the event story of the death could be valuable with clients bereaved by suicide or homicide, whereas additional attachment-informed work could be appropriate in exploring and extending the back story of the relationship in the case of the death of a child. In all such modifications, however, many opportunities are reserved for not merely

mitigating the overt symptoms of grief or promoting a generic form of behavioral activation, but also for engaging the multiple meanings of loss and its significance in the client's ongoing life.

The Case of Paula

To illustrate the application of the Meaning in Loss approach with an actual client, we will close with a description of its use with Paula (pseudonym), a 33-year-old woman who lost her 30-year-old husband, Antonio (pseudonym), 2 years earlier. At the start of therapy, she met diagnostic criteria for complicated grief according to the criteria proposed for the Prolonged Grief Disorder (PG-13; [51], adapted by [52]), and for major depressive disorder [23], as well as presented with general social withdrawal from her previously active friendship networks.

As months turned into years, Paula had remained preoccupied with the circumstances of Antonio's sudden death in his sleep. Despite all the family's efforts to understand why such a young and seemingly healthy man had lost his life unexpectedly, the autopsy report was inconclusive (*probably something congenital*, Paula told the therapist). Paula and Antonio had been married for 2 years and were in a relationship for almost seven, but had no children. Paula had struggled to carry on with her work in a retail business in the wake of this loss, but felt she had made little headway in overcoming the pervasive sadness and emptiness that had eroded her sense of hope and the quality of her relationships with others. She also struggled with a painful sense of unfairness and survivor guilt in being able to continue her life while Antonio, at such an early age, had been deprived of that right, missing all the life chapters they would have co-constructed in the many years they imagined they would have ahead of them. Chief among these dreams were the children they planned to have after Antonio returned from working in another country for the past year.

Paula entered therapy in response to media announcements about the availability of the Meaning In Loss therapy delivered via weekly, individualized teleconferencing with a specially trained therapist as part of a randomized controlled trial. In her therapy request Paula said, *I've tried to rebuild my life since then. It was difficult in the beginning but I'm trying to organize my routines step by step. I still find it difficult to accept what happened and to get emotionally connected with other people.* She started therapy describing herself as a person who *feared the future, who feared dreaming about what life might bring her* (which, according to her, was a clear departure from her previously optimistic self). Now, in contrast, she avoided thinking about moving into an unknown future that could bring more uncertainty and loss. As therapy moved from session 1 to session 2 and she felt she had a safe space to speak about her life and to reopen the story of her loss, she continued elaborating on how Antonio's death interrupted core life plans they built. As she explained, *"It is not just about getting married or having kids. It was about getting married and having kids with him that mattered."* She played part of their wedding video to session 2, giving the therapist a genuine sense of what she had and what she missed, reviewing the video, while tearful, also introduced the therapist to a defining moment in their relationship, describing who she was at that point, the hopes and dreams she and her husband shared, and who Antonio was "in life," not only as a dead person.

The reflection on this self-narrative discontinuity opened the door for the *chapters of life* technique in the next session, in which Paula segued from initial chapters entitled *Love and Life*—the names she chose to describe a period when she *learned how to love and to be loved.* As she elaborated *I cannot remember ever being so happy. I dreamed that this love would never end.* Cruelly, however, it did, as captured by a more recent and tragic chapter called *Death*, which in her view condemned her current life to being merely a *second choice*, one that would never be the life she chose and wanted in the first place. The day she learned Antonio was dead

began with a fateful telephone call only 2 days after he had gone to visit his parents in his hometown, where Paula would had planned to meet him that day. As she listened with disbelief, a friend's strained voice told her *something was not right* even before it spoke the words.

The external narrative that began with the call, her accompanying internal narrative of emotion, and the story of her struggle to make sense of what it all meant was deeply explored throughout the session, offering the opportunity for a slow-motion review of the most painful details of that day. Ultimately, the anguishing retelling promoted a fuller sense of coherence and emotion regulation than her previous attempts at avoidance had, as did the equally painful review of photos of Antonio and of the two of them together, as the therapist offered compassionate support and witnessing. Reflecting on the experience, Paula said "*my pain is a testimony of my love*," and found affirmation in the evocative lyrics by Brazilian singer Mariza Monte: *Se eu não tenho o meu amor, eu tenho a minha dor* ("If I don't have my love, I have my pain"), whose concert she bravely attended early in her therapy. These themes, of pain and love, wove through the performance, and seemed to presage two intertwined elements of Paula's life from Antonio's death on.

As different opportunities for reopening Paula's story of loss (sessions 1 and 2) and for scaffolding significant life episodes (session 3) had been explored, the therapist was now able to further engage Paula's story of the death using the meaning reconstruction interview (sessions 4 and 5). As she was encouraged to deepen into visualization of her loss, its associated embodied emotions and its impact in her life, Paula spontaneously described her journey as confronting a *dark and isolated corridor of a hotel with just an artificial yellow light*. In this metaphor, she was feeling immobilized, standing at the end of that corridor, basically wondering what—if any—movement was still possible.

This same sense of "*stuckness*" characterized Paula's initial attempt to communicate with Antonio through the letter work she and the therapist underwent in sessions 6

through eight. As she tried to write her husband a letter, she described feeling blocked, not knowing what to say, which she found strange as so much could have been said in the years since his death. More than the content of the letter itself (centered on how she missed him), it was this process of not knowing what to write that triggered a sense of guilt in her, as she now feared the possibility of “*forgetting him,*” as their communication was so abruptly interrupted 2 years before. The emergence of guilt and fear were then addressed in the response letter she wrote from the perspective of Antonio, which offered a compassionate response to Paula’s struggle with the first letter, as Antonio attempted to soothe and reassure her by saying *We will never forget “us.”* The same letter expressed support for her struggle to rebuild her life, because, as it movingly emphasized, he loved her and would always want to see her happy.

At this point, feeling released from the guilt, Paula shared that, for the first time in months, she could spend the weekend doing things *for* herself and *with* herself (e.g., going out, spending some time with friends, planning to invest in hobbies that she had enjoyed in the past), feeling relaxed and happy while engaged in each of these self-nurturing and self-enhancing activities. Simultaneously, she began planning to write a book to give voice to their story, capturing important memories and experiences she and Antonio shared. She noted how important it would be to share that book with her little nieces in the future, who had not had the opportunity to know Antonio, despite his being such an important person in their family. In these innovative moments of change, Paula testified to the relevance of the narrative resources from our daily life (e.g., to share our feelings with others, to write about our feelings and life experiences) to create more adaptive and coherent self-narratives.

This reopening of Paula’s sense of communication with Antonio and the subsequent telling of their story proved to be pivotal moments in the therapeutic process. This was further consolidated by the life imprint technique (session 9), highlighting the profound impact that Antonio had had on

her life, leaving tangible imprints on her sense of self that extended beyond his death. Linked with this reflection, Paula soon began to formulate new plans for embracing this future, such as taking at least one trip every year, spending more time with her family (especially her parents), enjoying the little moments in life, and being more present to others by, for example, doing volunteer work with homeless persons. These new resolutions connected the previous session (*life imprint*) that focused on Antonio's legacy to the present one that focuses on herself, thus bridging that legacy and the meaningful goals that now shape her life project.

As mentioned above, another pivotal theme in Paula's therapeutic process was the fear of the future, the fear of dreaming about what life could bring to her, in the face of further potential loss and disappointment. This theme reemerged in her *virtual dream story* (session 10). Paula set the story on a desert island, where she ended up after her boat capsized. While she was stranded on the beach, a little rabbit crossed her path, desperate to find his friend, the hedgehog. Paula agreed to help him find his friend, recapitulating metaphorically her own loss and search for a missing loved one. On that journey, Paula and the rabbit found a mysterious stranger who gave her a torn picture, and when she tried to put the pieces of that picture together she saw a younger version of herself with the little rabbit—perhaps she was the friend the rabbit was searching for, now having another form. At the end of the story, the sun rose again, and she was able to find her boat to return home. As she explored the imagery, plot, and themes of this story with the therapist, Paula reflected on how she enjoyed writing it and felt the desire to continue it, concluding, for example, that she and the rabbit already had known each other in the past. But most significantly, she appreciated the sense of finding herself again in the child portrayed in the picture, implying that that child was still there and still lived in her, creating a bridge of continuity between her past (a child that dreams) and present (an adult that fears to dream but that was once a hopeful child). Flexibly adapting the protocol, sessions 11 and 12 were

mainly centered on the preparation of rituals to perform on Antonio's birthday and at Christmas (which both occurred in the same week), as Paula expected these to be particularly challenging moments. Planning and completing several of these rituals, such as visiting Antonio's parents and exploring with them a box of significant mementos related to him, Paula found some sense of comfort and strength, as she thought, *if his parents are doing well, I can be well too*. Importantly, these rituals of reengagement were congruent with what she had formulated as a central goal, namely to spend more time with her family.

In session 13, the first session of the New Year, Paula told the therapist that she had written a letter to her husband on the last day of December, symbolically on the last page of her agenda, thereby creating a symbolic moment of transformation. She wrote him that he would live forever in her life but that she needed to open a new chapter now. By saying this, she acknowledged *a new desire to live the future*, her future. The metaphor of the corridor was revisited at this point, as Paula started sensing *some movement*, associated with an adrenaline rush as she confronted the anxiety of stepping toward the unknown. By reinterpreting and broadening the meaning of the corridor, she told the therapist that the corridor was a better option than having successive doors blocking her movement and preventing her from seeing what was in front of her. Now, in contrast, Paula and the therapist developed the corridor metaphor in new directions, reflecting on the meaning of the solid ground provided by the floor before her, and the sense of comfort and security afforded by the walls surrounding her, as she resumed her movement toward an unknown future.

Finally, in the last session of therapy (session 14), Paula described how she understood her process of transformation and her grief now, feeling that she no longer had to force herself to find a *cure* or to accept the *unacceptable* (which marked a clear contrast with what she had written on her initial clinical request, which referred to her pathological inability to *accept what happened*). Summarizing her sense of

change across therapy, she noted that the therapeutic process helped her to *understand that [she could] embrace suffering but continue to live [her] life... and to reconstruct a new life story*. To illustrate the magnitude of this meaning reconstruction, she shared with the therapist that she had started a new romantic relationship. Moreover, she felt that Antonio would be proud of her ability to rebuild a life of love and happiness. In a remarkable ending ritual, she read a letter that Antonio would have written to her at that moment:

Since the day I met you, I wished to make you happy. I will never leave you, I will always live inside of you, through you! Today, as always, I want to see you happy, I want you to live, to overcome all challenges, to "take" the future... Life is an unknown, things don't always happen the way we want, as we know... but it's always worth a try.

Finally, she read a Buddhist inspired quote that depicted her continuing bond with her husband, as if Antonio were speaking these very words to her:

I will always be here, in the wind, in the ocean. And if you love me, if you trust me, you will feel me in 1001 ways... In your moments of silence you will suddenly feel my presence. As I'm not a body anymore, my conscience is universal. So you don't need to try to find me. Wherever I am, your thirst, your love will find me in your heart, in the beating of your heart.

At the completion of therapy, Paula no longer met criteria for a diagnosis of CG or major depression. This reduction of both sets of symptoms was maintained 3 and 6 months after therapy termination.

Concluding Thoughts

In this chapter, we have argued that grieving, when viewed through a narrative constructivist lens, can usefully be seen as a process of reaffirming or reconstructing a world of meaning that has been challenged by loss [40]. We then reviewed some of the growing body of empirical studies suggesting the central role of meaning-making in adapting to bereavement, and

conceptualized the narrative challenge posed by the death of a loved one as encompassing a need to process both the *event story* of the death itself and the *back story* of the relationship to the deceased. When these facets of meaning reconstruction are successful—as they commonly are without the need for professional intervention—survivors are able to integrate the experience of loss and re-access the relationship in a way that provides some measure of attachment security as they move forward with a changed life that nonetheless has meaning and purpose.

However, we also recognize that for a significant minority of the bereaved, the challenges posed by the death will prove complicating and impairing across a prolonged period, at great cost to their physical, psychological, social and perhaps spiritual well-being. In such cases, we have contended that professional intervention can help people find a way forward in the landscape of a life story made alien by loss, and that narrative techniques like those that comprise the Meaning In Loss protocol can make a contribution to this effort. As a flexible framework for addressing the major ruptures in the client's world of meaning occasioned by the death, the Meaning In Loss protocol structure can be readily adapted to different populations of mourners, as our collaborative research in the USA, the UK, Canada, and Portugal demonstrates.¹

Likewise, we are encouraged by the adaptability of the protocol to different formats of therapy as evidenced by its successful implementation in both face-to-face and videoconference therapies. Indeed, we have found each of these formats to offer distinct advantages, as well as corresponding limitations. On the one hand, face-to-face groups augment the individual efforts of clients and therapists by underscoring the universality of grief, the vicarious learning from

¹ In particular, we would like to acknowledge Evgenia (Jane) Milman of McGill University in Montreal, Edith Stefan of Roehampton University in London, Inês Mendes of the University of Minho, and the growing network of capable colleagues and trainees who have served alongside us as therapists in adapting the Meaning In Loss protocol to the needs of their grieving clients.

others, and the contagion of hope that is characteristic of most process-oriented group therapies [53]. Beyond these general advantages, the Meaning In Loss group also utilizes frequent dyadic and triadic pairing of clients throughout the therapy to facilitate their sharing their reflective writing, processing between-session assignments, and bridging from the intimate support of one other person to the construction of a secure base with the entire group. However, even with the extension of therapy from the single hour typical of individual work to the 2 h that might be spent in a weekly group, the presence of 8–10 clients, each with his or her own unique stories of loss, necessarily reduces the amount of time a therapist or co-therapist team can spend with any one of them. We have therefore found that pre-screening interviews with potential referrals to the group are of great value in assessing prospective clients' unique losses and corresponding needs and their ability to work well with others, while also building a germinal sense of trust with the therapist. When bereaved individuals are clearly in crisis, struggle with potentially lethal suicide ideation, or are unable to step beyond their own pain to validate that of another, referral to individual therapy may be the better option.

In conclusion, we have found a meaning reconstruction model to provide an increasingly well-researched and robust approach to the potential complications of bereavement, and hope that readers might find in it some creative, empirically informed procedures that could enrich their efforts to help bereaved clients.

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Chapter 9

Helping Grieving Children and Adolescents

Cynthia Moore

There are few situations that arouse more concern and compassion in adults than being in the presence of a grieving child. Particularly after parental loss, many adults may wish to offer support, but have varying opinions about what the child most needs at any given time. A surviving parent might hear, for example, “You have her in therapy, right?” “Kids are resilient, he’ll be ok in time.” “I heard about a great summer camp program you should look into—kids need other kids so they know they’re not alone.” “You should make sure her school counselor is checking in on her every week.” A rich support system is certainly an asset for any family, but caregivers of a grieving child may feel confused by the potentially conflicting advice from this network. On the other hand, parents with limited social connections who may be grieving themselves, or facing employment, financial, health, or other stressors, can struggle to generate *any* feasible options to support their child.

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Providers in a variety of settings have the opportunity to guide parents to recognize the needs of bereaved children, and decide how best to meet them. With this in mind, this chapter reviews research on approaches for working with grieving children and describes treatment indications and recommendations to aid in tailoring treatment to an individual child's needs.

Grief: Normal Process or Treatable Condition?

One of the debates underlying any discussion of “treatments” for grief concerns the question of how grief is defined, and what goals the intervention sets. Additionally, the debate over creating a diagnostic category for complicated grief/prolonged grief disorder in the DSM-5 highlighted concern over the possibility that some in the mental health community are pathologizing grief and ultimately stigmatizing the bereaved [1]. Is grief best understood as an always normal, though painful, healing process in response to a loss? Or acknowledged as sometimes resulting in a more disruptive response associated with significant psychological morbidity? Parents' understanding of grief contributes to the likelihood they will seek treatment for a bereaved child.

“Typical” Grief

Grief is commonly described as a gradual adaptation to the loss of a loved one, entailing particular tasks. These include accepting the reality of the loss, facing and bearing the associated pain, adjusting to an environment and self-identity in which the deceased is missing, finding meaning, maintaining an internal connection to the deceased, and re-engaging in life and new relationships [2, 3]. Each of these tasks poses unique challenges, affected by child and family characteristics. For example, openness of a family's communication can

contribute to the ease and timing of a child's accepting the reality of the loss, and a child's temperament and emotion regulation abilities will affect how emotional pain is experienced and expressed [4].

Grief reactions look and feel different in early vs. later forms. Acute grief is the initial response to a loss, often intense, disruptive, and difficult to ignore. Over time, acute grief evolves into integrated grief, a permanent background state in which the griever may still experience distress about the loss, but also comfort in memories of the deceased and renewed satisfaction in ongoing life [1]. The dual-process model of grief [5] posits that positive adjustment to death, or in Shear's terms [1], adaptation from acute to integrated grief, occurs through a focus on loss-related emotions and cognitions oscillating with restoration-oriented tasks. A single event can involve both kinds of tasks, not necessarily equally challenging. For instance, a bereaved child might need to learn to manage intense sadness about missing her mother's special way of tucking her in at bedtime, as well as develop a new bedtime routine that involves an adult's help organizing her for the morning and then transitioning to sleep.

Psychiatric Sequelae

As detailed in Chap. 4, most grieving children experience a period of heightened emotional distress after a loss, including feelings of anxiety, sadness, and anger, that subsides over time. Although bereaved children and adolescents are at higher risk for developing psychiatric disorders like major depression or post-traumatic stress disorder (PTSD) after a loss, most do not. For example, in a group of 7–18-year-old children who had a parent die suddenly from natural causes, suicide, or an accident, about 24% experienced an episode of major depression within 9 months of the loss and 8.6% developed PTSD, compared to 5.4% of non-bereaved controls who developed depression, and 0% PTSD in that same time period [6, 7]. By 21 months post-loss, 10.2% of bereaved,

vs. 2.4% of controls, had current major depressive disorder, while PTSD had remitted in 93% of the bereaved youth. Major depressive disorder, PTSD, or other diagnosable conditions are not simply understandable reactions to a loss and warrant intervention when present.

Traumatic Grief, Complicated Grief, or Prolonged Grief Disorder

Over the past three decades [8], research has focused on ways that complications in the natural grief process can derail and prevent grief from becoming integrated. This can result in a constellation of symptoms associated with significant distress and dysfunction, referred to in the literature as Complicated Grief, Traumatic Grief, Prolonged Grief Disorder, and in the DSM-5 as Persistent Complex Bereavement Disorder [1]. Consistent with other chapters, we will assume that these clinical entities refer to a single phenomenon. As defined by research in adults, central features include separation distress and yearning for the deceased, and a number of studies extend these findings to bereaved children (e.g., [9, 10]). Research rooted in work on child trauma and focused on children who lost a loved one in subjectively traumatic circumstances yielded the overlapping but separate construct of childhood traumatic grief (CTG). This describes children who develop trauma symptoms that impinge on their ability to engage in the typical tasks of grieving [11, 12]. While the field has yet to settle on a unified definition of this complicated and prolonged form of grief in children, links between these reactions and heightened, longer-term dysfunction [9] suggest the merit of providing ongoing assessment and treatment when its presence is suspected.

Treatment Efficacy

Before exploring bereavement interventions for children in more detail, it makes sense to ask whether “grief therapy” is helpful. Two meta-analyses provide a useful starting point for

examining the overall effectiveness of such interventions for children. Currier et al. [13] examined 13 studies that included a control group, totaling 783 children. Most treatments occurred in a group format beginning on average 1.5 years after the death. Treatments aimed to improve coping and understanding of death and grief, and allow the child to express grief-related feelings. The authors reported a nonsignificant average effect size of Cohen's $d = 0.14$ and concluded that, overall, treated children did not fare better than those who did not participate in grief therapy. Rosner et al. [14] analyzed 13 controlled studies (73% overlap with Currier's list) as well as 12 uncontrolled studies, including a total of 1073 youth. In contrast to Currier et al. [13], they reported omnibus effect sizes of Cohen's $d = 0.37$ for controlled, and of $d = 0.49$ for uncontrolled studies, indicating a small to moderate treatment effect. Further, a comprehensive review of treatment efficacy studies on both children and adults reported a small, but significant effect for randomized studies (Cohen's $d = 0.16$) and a moderate effect for non-randomized studies (Cohen's $d = 0.51$) [15]. Overall, then, grief treatments as a group have not been shown to perform as well as general psychotherapy with children with identified psychiatric conditions, and there is mixed evidence as to whether they work at all.

Why might this be? In part, the natural attenuation of grief symptoms without treatment makes showing positive effects of therapy more challenging and partly explains why controlled studies show smaller effects than uncontrolled studies. Studies that examined many outcomes, such as the Family Bereavement Project described below, showed a mix of statistically significant and nonsignificant effects, which results in a smaller average effect size despite success in producing clinically important improvements. Findings about parent responses to these treatments were not included in meta-analyses, though parenting is a critical predictor and moderator of child adjustment to a loss [16]. More fine-grained exploration within one meta-analysis of uncontrolled studies found larger treatment effect sizes for grief and PTSD symptoms, compared to depression and other outcomes, suggesting

a differential treatment effect depending on the outcomes of interest [14]. Finally, results from meta-analyses are only as strong as the studies themselves, and the number of well-designed studies using well-validated measures of a range of outcomes, control groups, and follow-up over multiple time points is very limited. The field is not yet sophisticated enough to provide definitive guidelines about which treatment, if any, is best suited to an individual child's symptom profile.

Despite this uncertain empirical base, an understanding of the overarching goals of different types of interventions can inform the practical treatment decisions caregivers and providers face. *Universal interventions* may be provided to any bereaved child regardless of level of distress. They include the many grief support programs that focus on promoting positive adaptation to loss, without an explicit focus on preventing specific negative outcomes. *Selective interventions* target children whose loss has the potential to cause high distress, such as suicide survivors, or children who witnessed the death. Finally, *indicated interventions* attempt to reverse or treat already occurring maladaptive grief reactions or other psychiatric disorders.

Three interventions are discussed next in some detail to highlight both the overlap in relatively effective methods and the range of methods that can have a positive impact.

Treatment Approaches

Supporting Resilience: The Family Bereavement Program

In the mid-1990s, psychologists at Arizona State University (ASU) developed a theory-based intervention designed to prevent a range of negative outcomes by targeting known risk factors for poorer adaptation in bereaved children and their families. While it has not yet been broadly implemented, efforts are ongoing to disseminate the model in a manner that preserves treatment fidelity, as well as to identify critical treatment ingredients (personal communication, Sandler 2017).

The Family Bereavement Program (FBP) sets two main goals: to decrease children's exposure to the cascade of stressful events that often follow parental death, such as caregiver concern about finances or conflicts among extended family members, and to strengthen child and family resources for dealing with a range of stressors. Both problematic and positive aspects of functioning, such as mental health symptoms, problematic grief, academic competence, and self-esteem, are targets for change, as are multiple potentially malleable risk and protective factors demonstrated in prior research to impact children's adjustment to a parent's death [16, 17]. A positive parent-child relationship is highlighted as the most consistently supported mediator of child adjustment after a loss and therefore a key interventional target.

Groups for youth are designed to teach skills that promote effective communication and positive relationships with caregivers, teach active coping strategies, decrease negative thoughts about stressors, improve self-esteem, clarify what the child can and cannot control, and increase adaptive emotional expression [16–18]. Psycho-education about the grief process is also provided. For example, children are taught that death is never the child's fault, it is not unusual to think they see the parent, and that strategies such as talking about positive memories can help maintain an ongoing internal relationship with the parent [18].

Caregiver groups are designed to promote positive parenting (demonstrated affection and warmth, open communication, reflective listening, effective discipline) and to improve caregiver mental health. In addition, caregivers are taught how to reduce children's exposure to negative events, like financial concerns or stressful changes in routines. The caregiver and child/adolescent programs run in parallel and include 12 two-hour sessions, some including conjoint activities for caregivers and youth, and two additional individual 1-h sessions for caregivers. Groups are led by two Master's level clinicians and incorporate didactic teaching, modeling, and role-playing to facilitate mastery of new skills. Detailed manuals and training are available from the ASU Prevention Research Center (see "Appendix" for details).

The efficacy of the FBP has been evaluated longitudinally over 15 years in a group of bereaved children between 8 and 16 years old and between 4 and 30 months post-loss (average 10 months) at program entry, who were randomly assigned to the intervention program (90 families, 135 children) or a self-study bibliotherapy program (66 families, 109 children). While no minimum level of distress was set, families were excluded from the study if either the caregiver or child was already receiving other mental health or bereavement services or expressed suicidal intent, if the caregiver had current major depression, or the child had oppositional defiant disorder, conduct disorder, or attention-deficit/hyperactive disorder not being treated with medication [16].

While child mental health symptoms did not differ between groups immediately after the program concluded, by the 11-month follow-up, participation in the FBP resulted in reduced internalizing (anxiety, depression, somatic) and externalizing (disruptive, hyperactive, and aggressive) symptoms for girls, and lower internalizing symptoms for the boys and girls with high levels at baseline. Girls in the self-study condition showed no reduction in internalizing or externalizing problems over time, whereas boys in both groups showed decreases over time [16]. Normative grief symptoms for FBP participants decreased more quickly than for controls over the time of the intervention. Among children with scores in the highest 20% on a measure of intrusive grief-related experiences, 68% of FBP participants vs. 33% of controls were below this cutoff at post-test at the end of the intervention [19].

At the six-year follow-up, child participants in the FBP had fewer externalizing symptoms [20], as well as higher levels of cortisol output, an indicator of improved reaction to stress via better HPA-axis functioning [21]. They had lower levels of intrusive grief symptoms, with a small to moderate effect size ($d = 0.41$), and younger children in the FBP group showed higher self-esteem and improved academic performance [17]. Additionally, program participation was found to reduce suicidal ideation and attempts at the 15-year follow-up [22].

Caregivers also benefitted from participation. Mental health problems in the FBP group were significantly reduced compared to controls after the group ended, with differences trending significance at the 11-month follow-up [16]. Further, those assigned to FBP exhibited lower levels of depressive symptoms, general psychiatric distress, prolonged grief, and alcohol problems, and mothers had higher coping efficacy at the 6-year follow-up [23].

What accounted for the improved mental health, grief, and neuroendocrine outcomes for the children who participated in the FBP? Improvements in many of the study variables were linked to positive outcomes, suggesting that the approach of targeting a range of risk factors to promote resilience was effective. For example, improvements in positive coping, accurate threat appraisal, and realistic beliefs about control mediated program effects on girls' mental health at 11-month follow-up [20]. But changes in two areas are particularly important to mention. First, parents in the FBP group gained positive parenting skills such as increased warmth and effective discipline, which were sustained through both the 11-month and the 6-year follow-ups. These were in turn likely reinforced by complementary skills learned by children, as well as children's ongoing positive responses to parents using these skills [24]. Second, FBP parents were able to minimize the cascade of negative life events in children's lives following the loss of their spouse. Both of these changes mediated improvements in many outcomes in children, across multiple time points.

FBP authors emphasize the need to educate providers about the importance of positive parenting (specifically warmth, open communication, and effective discipline), increasing positive events and shielding children from strong adult emotions. In addition, they suggest that interventions need to provide an environment in which a child can understand grief and develop cognitive and behavioral skills they can use to handle the challenges related to the death [18]. While the program has not yet been tested in children with

high levels of externalizing problems, the structured format and use of group contingencies, such as giving the group points toward a prize for practicing skills at home, may facilitate its use in this group as well.

Treating Traumatic Grief: Individual and Group Approaches

As noted above, childhood traumatic grief (CTG) is conceptualized as occurring when children whose loved ones die in subjectively traumatic circumstances develop trauma symptoms, which interfere with engagement in the typical tasks of grieving. For instance, affective, cognitive, and behavioral difficulties linked to traumatic circumstances of the death, such as avoidance of reminders of the deceased and emotional numbing, may disrupt reminiscing, processing painful emotions, adapting to the implications of the loss, and making meaning of the death [12]. The Child and Adolescent Trauma Treatments and Services (CATS) Consortium utilized two programs showing particular promise to treat CTG in a large project associated with the September 11 World Trade Center disaster [25], discussed next.

Trauma-Focused Cognitive Behavior Therapy (TF-CBT)

TF-CBT is an individual, components-based therapy model with well-validated effectiveness as a treatment for children with PTSD (e.g., [26, 27]) which has been expanded to address the needs of children with traumatic grief through the addition of grief-focused modules. While no randomized controlled trials of the program's effectiveness treating traumatic grief have yet been conducted, initial (uncontrolled) studies suggest it is a promising approach for this population

as well [28, 29]. The phased treatment addresses first trauma, then grief symptoms and incorporates individual child and parent sessions as well as conjoint sessions. Including parents helps them support children in practicing new skills, and also cope better with their own trauma symptoms [30].

Treatment components include psycho-education about trauma and grief; parenting skills (including the use of praise, selective attention, effective time-out procedures, and behavior charts); relaxation skills (such as breathing exercises as well as guidance in developing new, comforting rituals that do not trigger trauma or loss reminders for the parent or child); affective expression and modulation (such as using thought interruption and positive imagery strategies, problem-solving, social skills building, self-soothing); and cognitive coping and processing.

Over several sessions, children are guided to develop a trauma narrative that successively includes more details of what happened before, during, and after the traumatic events, as well as thoughts or feelings during these times. A primary goal of this exercise is to desensitize the child to traumatic reminders, and reduce avoidance, hyperarousal, and overwhelming negative emotions like terror, horror, shame, or rage. Creating this narrative may also enable the child to integrate the traumatic experience into the totality of his life, and see it as only one part of his life experience and self-concept, rather than the defining aspect of both. In vivo practice coping with trauma reminders contributes to these goals as well [30].

Specific grief-related modules were designed to help resolve ambivalent feelings (listing “what I miss” and “what I don’t miss”), preserve positive memories (for example, by creating a memory box or video), redefine the relationship with the deceased, and commit to present relationships (drawing what is kept and what is lost in the relationship).

Studies of the full 16-session protocol [28] and an abbreviated 12-session version [30] found significant improvements from pre- to post-intervention in traumatic grief, PTSD, depression, anxiety, and behavior problems in children.

Parents also had decreases in PTSD. Interestingly, children's PTSD symptoms decreased during the trauma-focused module, but traumatic grief symptoms improved during both the trauma and grief-focused modules. A group protocol for TF-CBT with grief components has also been tested in an open trial in Tanzanian children who had symptoms of grief or post-traumatic stress (PTS) sustained at least 6 months after the loss of a parent. Children showed improvements in grief, PTS, and depression symptoms by end of treatment and at follow-ups at 3 and 12 months. Those children with more symptoms at baseline showed the biggest improvements, but boys and girls, and children of different ages, benefitted equally [31]. Further, this field trial, along with the CATS Consortium work post-9/11, demonstrates the feasibility of training counselors with varied background and experience to offer this treatment with good effect.

Certainly, the lack of studies using a no-treatment comparison group with follow-up beyond the treatment time frame limits confidence in TF-CBT's effectiveness for helping children with traumatic grief vs. only trauma. However, it remains an extremely promising approach in improving outcomes for both individual children and their parents. Free training and a listing of certified TF-CBT therapists are available online (see "Appendix").

Trauma and Grief Component Therapy for Adolescents (TGCT-A)

TGCT-A, developed by the UCLA Trauma Psychiatry Service team, was designed to reduce distress and dysfunction, enhance positive adaptation, and promote healthy development in children whose exposure to trauma, traumatic loss, and severe adversity places them at high risk for distress and functional impairment [32, 33]. It is a flexible, school-based group psychotherapy program, with specific components prescribed based on assessment results. The program systematically screens large groups of public school

students for trauma exposure and distress, and students who endorse significant levels of both are invited to participate in an individual screening interview which explores functional impairments at home, school and with peers, and determines appropriateness for individual or group therapy.

Next, students complete a pre-group clinical interview, which identifies key features of the traumatic experience, negative emotions, and current psychosocial adversities, and creates a hierarchy of trauma and loss experiences and an inventory of trauma reminders. Psycho-education about traumatic stress and complicated grief is also provided at this stage [34]. Adolescents who meet criteria for distress and appropriateness after this multistep screening participate in a manualized, school-based treatment protocol designed to reduce distress in targeted grief and trauma-focused outcomes.

The consistent format for each session includes a check-in activity, review of practice exercises from the previous week, presentation of information and skills coupled with a group activity, assignment of home practice, and a check-out exercise. The 20 sessions comprise four modules. The first focuses on building group cohesion, providing psycho-education, and developing skills to cope with trauma-related distress. The second module focuses on processing selected traumatic experiences by completing trauma narrative exposure work, exploring the worst moments to increase tolerance, and restructuring maladaptive cognitions associated with negative emotions. Module 3 works with the interplay between trauma, loss, and grief, and provides education about grief symptoms and loss reminders, processing anger, and reconstructing a nontraumatic image of the deceased. The final module focuses on problem-solving around current adversities, challenging maladaptive core beliefs, and taking steps to re-engage in normal developmental activities [33].

Versions of TGCT-A have been evaluated in uncontrolled trials in various field settings, including in US students exposed to community violence [33] and in New York City

following the September 11th terrorist attacks [25], as well as in post-war Bosnia [32]. Findings across these studies revealed improvements in PTSD and complicated grief symptoms. A randomized controlled evaluation compared only the psycho-education and skills modules against all four modules and found that approximately 81% of youth reported significant reductions in PTSD and 61% in depressive symptoms at 4-month follow-up in the TCGT-A group, compared to 48% (PTSD) and 47% (depression) in students in the comparison condition. Further, only the youth in the full TGCT-A condition showed significant reductions in complicated grief symptoms [32].

A pilot study of 33 adolescents explored how constructing either a trauma-focused or loss-focused narrative impacted symptom change. While both groups of students experienced reduction in PTSD and “maladaptive grief (MG) reactions,” those whose narrative focused on loss showed steeper declines in MG over treatment [35]. Also, adolescents with more internalizing problems showed more improvement during the later, narrative construction phase of treatment, while students high in externalizing symptoms showed more immediate gains during the initial skill-building phase of treatment [36]. While these results need replication, they suggest strategies to tailor interventions so they better address co-occurring symptoms.

Fact sheets describing TF-CBT and TGCT-A can be found on the National Child Traumatic Stress Network (NCTSN) website (see “Appendix”). While sharing common components, the two approaches differ in their appropriateness for younger children, emphasis on parent participation, screening process, and availability of handouts in languages other than English.

Peer-Based Grief Support Programs

It is worth considering the more general “grief support” programs largely because of their popularity—a Google search for “grief support group child” returned 1.4 million

results. National and local nonprofit organizations, professional associations, and even funeral homes offer information on children's grief. A variety of peer-based support groups and weekend camps are described. Mission statements for a few of these programs, lightly edited, indicate that programs aim to provide free grief resources, resilience training, and ongoing support; maximize children's well-being using a peer support model that facilitates safety and belonging; and empower children to grieve, heal, and grow in healthy ways. These programs are often staffed by nonprofessional volunteers with varying levels of training. It is impossible to judge the effectiveness of many grief support programs that parents may discover because they tend not to undergo rigorous (or any) evaluation.

However, the overall focus on providing comfort and companionship to grieving children may be of interest to some families. Should a parent enroll their child in such a program? Children or families who feel these opportunities would provide a welcome distraction, opportunity for new supportive relationships, or who hope to experience a sense of belonging in the company of others with similar life experiences, may find these programs meaningful and enjoyable. In the absence of any evaluative data, it probably does not make sense for parents to insist that a reluctant child attend, and parents should always ask questions: how are group leaders trained and supervised? When is information about what a child shares in a group conveyed to a parent? Does the program ever suggest a referral to a professional mental health provider, and what would trigger this? How much emphasis is placed on allowing children to participate, or not, depending on their comfort level, and can children leave the room if what others share becomes too challenging? How much is the focus on talking vs. physical activities, and how will this fit the style of a particular child? How are challenging behaviors among group members handled by leaders? Parents may then want to describe the group to the child, and talk together about whether it feels like a good fit. It is important that

parents not assume that a child who shows signs of persistent or severe emotional or behavioral disruption is adequately supported by a grief support group operating from an unevaluated model.

When and Whom Should We Treat?

Timing of Treatment

The meta-analyses described earlier explored whether treatments provided when losses were more recent showed better outcomes. Currier et al. [13] found this to be the case, and suggested that treatments overall were not found to be more effective because many were delivered after children and families had already accommodated to the loss, so the main treatment objectives were no longer well-suited to the child's needs. Brent et al. [6] highlighted the first 9 months after a loss as a window of opportunity to prevent or attenuate future depression. However, Rosner et al. [14] did not find differences in treatment efficacy based on time since bereavement, suggesting that treatment can be beneficial even well after the loss has occurred. Timing of treatment in relation to a loss is thus an area needing additional research.

Who Benefits Most?

Existing research hints that more distressed children benefit more from treatment [13, 14], but there is not enough certainty in this finding to justify excluding a child from treatment who does not meet a particular distress level cutoff. At the same time, Jordan and Neimeyer [37] suggest that a substantial minority of adult griever may have actually achieved a better outcome had they been assigned to a control rather than an intervention condition, implying that we should remain cautious about urging all bereaved children into treatment with the unproven idea that, "it can't hurt."

Taking this all into account, how can caregivers make an informed decision about whether to seek support for a grieving child? Knowing that many children adapt to a loss without experiencing major psychiatric sequelae may alleviate guilt for parents who are not inclined to automatically seek counseling. Yet, awareness that a subset of grieving children develop symptoms that cause significant and persistent impairment at school, with peers and at home, may prevent parents from too quickly writing these symptoms off as simply an understandable reaction to loss. Choice of treatment will depend on the family's unique circumstances, but Table 9.1 describes some general guidelines for matching treatment to clinical presentation.

Even in the absence of current emotional/psychiatric dysfunction (Indication 1 in Table 9.1) or significant risk factors for future dysfunction (Indication 2), managing the cascade of changes that attend the death of a caregiver (Indication 3) can be extremely stressful for children. How numerous and significant these changes are varies widely across families, and the broader context in which they occur impacts the child's perception of stress. For example, a child

TABLE 9.1 Treatment indications and recommendations

Indication	Recommendation
Does the child show clinically elevated grief-related distress, depression, anxiety or functional impairment on objective, normed measures of functioning?	<p>If so, assessment and treatment with a qualified mental health professional is recommended to reduce current distress and to prevent future impairment. If a child reveals suicidal ideation or intent, or engages in risky or self-harming behavior, urgent evaluation and safety planning is critical</p> <ul style="list-style-type: none"> <li data-bbox="519 1301 874 1419">• Consider TF-CBT, TGCT-A for children who experienced a loss with subjectively traumatic features

(continued)

TABLE 9.1 (continued)

Indication	Recommendation
Does the child have one or more risk factors for heightened distress or dysfunction, or is the child asking to see a therapist? ^a	If so, and particularly if multiple risk factors are present, treatment aimed at ameliorating the risk, likely with a professional mental health provider, is indicated.
<ul style="list-style-type: none"> • Child factors: prior psychiatric disorder, especially depression or anxiety; high number of negative life events; low self-esteem; negative coping style/poor expressive coping; belief that others are accountable for the death, or that others blame the child for the death • Caregiver factors: poor caregiver mental health and functioning, especially depression; expression of strong emotional distress in response to the death; low levels of child-centered parenting, parental support and communication; history of bipolar disorder in the deceased parent • Family factors: low family cohesion and low adaptability • Loss factors: protracted illness, being at the scene when a sudden death occurred; parental suicide 	<ul style="list-style-type: none"> • Consider returning to a provider who was helpful in the past, for children with pre-existing mental health issues • Consider school-based resources and the match between the expertise and school-year availability of staff, with the child's needs and preference for school to remain an "island of normalcy" where grief is not a focus • When resources are limited, consider supportive interventions such as Big Brother/Big Sister programs that strengthen the child's connection to stable, supportive adults; be careful about programs with high turnover, however, to prevent additional losses • Consider individual therapy or group supports for caregivers with significant mental health issues • Consider individual or group parent guidance to promote positive parenting practices

TABLE 9.1 (continued)

Indication	Recommendation
<p>Does the child feel generally well-supported by adults and peers in his or her day-to-day environment but overwhelmed by particular challenges at school, with friends, during activities, or at home with family? For example:</p> <ul style="list-style-type: none"> • Difficulty on math tests that do not seem to be part of a broader drop in grades suggestive of depression, but rather an adjustment to loss of a parent who structured study time and provided “cheerleading” • Worry about “breaking down” in front of peers at school in response to loss reminders • Irritation/fighting with a sibling who is grieving differently and may seem uncaring 	<p>If so, consider what kinds of targeted approaches might broaden and deepen the child’s social support network, and improve coping skills in a way that takes into account the child’s unique personality, temperament, and strengths. For example:</p> <ul style="list-style-type: none"> • Tutoring from an older student • An initial scheduled check-in with a school guidance counselor to increase child’s comfort with accessing that person and to develop a coping plan for managing distress during the school day • Parent guidance/psycho-education about normalizing a range of grief reactions, impact of developmental stage on grief, and strategies to talk with children about these differences

^aBased on findings reported in [6, 7, 9, 11, 28, 38–42]

with a previous history of being bullied at school and no really close friend will likely struggle more with getting teased about a deceased parent than a child with a long-time best friend who also likes and trusts his teacher. A military-connected child whose parent’s death forces an eventual move from a military base, with its strong network of support, to a neighborhood of civilians may find the change in location challenging but the change in culture even more so.

Thus, clarifying the child's *own* perception of support from home, school, and peers is a critical step in fully assessing the need for any kind of treatment.

It Takes a Village

The importance of support to parents and caregivers as they care for grieving children should not be underestimated. Providers from a range of backgrounds—mental health, medical, and educational—have much to offer parents and, indirectly, their children. Suggestions, based on clinical experience, for providing guidance to parents in supporting their children are presented in Table 9.2. For example, providers might help parents reframe efforts at self-care not as selfish, but rather as a means to facilitate children's well-being by setting a positive example and optimizing their functioning in the parenting role. Expressing genuine interest about a parent's experience caring for a grieving child will likely reveal

TABLE 9.2 Helping parents help children

Parents can	Providers can
Provide praise, warmth, and consistent limits—these are critical to children of all ages	Develop comfort in screening children for distress and a rationale for recommending treatment
Proactively identify signs that a child with a pre-existing psychological vulnerability could be relapsing. What helped in the past, and what can be done in advance to facilitate timely access to support? Internalizing symptoms are often under-recognized, especially in adolescents, so don't set too high of a threshold for accessing support	Learn about resources in your area. Do they provide grief support for all children, or treatment for those with high levels of distress? Develop resource lists for parents. Consider training in an evidence-based approach, individually or with colleagues

TABLE 9.2 (continued)

Parents can	Providers can
Talk with children about grief, but do not assume all negative emotion is grief-related. Even children with no loss history have bad days	Inquire about grief-related distress, and also about developmental competencies and strengths; both are indicators of functioning after a loss
Communicate with the school: how does the child function there? What books or units may be challenging for the child (e.g., science unit on cancer) and what support can be offered? With the child, develop a plan for what to do if he/she becomes emotional during the day (visit nurse or counselor? text a parent?)	Understand and educate about trauma and loss reminders and the importance of not setting up a cycle of avoidance because it so often generalizes to new situations/settings
Identify difficult dates for family members (e.g., major holidays, the birthday of the deceased) and know that their approach may explain heightened reactions that may otherwise seem mysterious	With parents, consider how to manage difficult dates: will the deceased be remembered aloud and is this comfortable for all family members? Are there arrangements (new location for holiday) or agreements (we will ask extended family not to ask children how they're doing) that might help?
For therapy-reluctant children, reframe as a way to thrive despite adversity, or an opportunity to develop skills useful in athletic and academic settings as well as close relationships. Try sharing that the primary motivation is to assuage your own uncertainty about recognizing distress, rather than a response to particular signals from the child	For therapy-reluctant parents, reframe getting their own support as one of the best ways of helping their children, not a luxury, given the strong connections between caregiver mental health, parenting, and child outcomes. Remind them that it is difficult to keep a child afloat when you, yourself are drowning

opportunities for support and comfort. Given the opportunity to talk, some parents will share that they are deeply afraid that the death of a loved one might ruin their child's life forever. Conveying that bereaved children can grow up to lead productive lives and find people to love and be loved by, can be enormously helpful to parents. Perhaps most important is the assurance that *you* will support them in ensuring their children thrive.

Appendix

Family Bereavement Program

- For program and training information, see <https://reachinstitute.asu.edu/programs/family-bereavement>
- Intervention manuals for the child, adolescent, and parent programs are available from the Prevention Research Center, Arizona State University, 900 S. McAllister Ave. Room 205, P.O. Boxes 876,005, Tempe, AZ 85287–6005.

Trauma-Focused Cognitive Behavior Therapy (TF-CBT) for Childhood Traumatic Grief

- Free web-based training available at CTGWeb: www.musc.edu/ctg
- Free web-based TF-CBT consultation program (Funded by the Annie E. Casey Foundation) available at www.musc.edu/tfcbtconsult
- For a list of certified therapists, see <https://tfcbt.org/members>

Trauma and Grief Component Therapy for Adolescents (TGCT-A)

- Layne CM, Saltzman WR, Pynoos RS. Component Therapy for Trauma and Grief: Adolescent Version. University of California, Los Angeles; 2002.
- Contact the authors for training.

National Child Traumatic Stress Network (NCTSN)

- For information on TF-CBT and TCGT-A as well as other evidence-based treatments, see <http://www.nctsn.org/resources/topics/treatments-that-work/promising-practices>

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Chapter 10

Supporting Grieving Students in the Aftermath of a School Crisis

David J. Schonfeld and Thomas Demaria

Schools have ongoing supportive relationships with the students and are well suited to provide support for grieving children because school staff are already familiar to the students and trusted by their families and they have ongoing supportive relationships with the children [1]. Schools can provide psychoeducation, model and teach effective coping strategies, and provide academic and other supports to grieving students. They have established mechanisms of routine monitoring of the adjustment of children over time and can facilitate referral to community-based bereavement support services (e.g., bereavement support groups and camps) as well as referral to mental health services for those children in

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need of additional support. In addition, schools are increasingly becoming more adept at handling crisis responses; well-established guidelines for crisis preparedness and response and training of school crisis teams are now available [2–4].

Support of grieving students after a school crisis event also poses multiple challenges. When children are surrounded by peers who have also experienced loss, the grief may appear to be magnified as children pick up the distress in their peers, as well as the adult staff in the school. Information often spreads quickly through discussions among students and via social media, often propagating rumors or inaccurate information which may intensify anxiety and distress [5]. Even if the school community has a shared experience of loss or trauma, students will bring to the experience a wide range of prior experiences, pre-existing mental health challenges, concurrent losses or stressors, family support systems, and personal coping abilities. The strength of their relationship or their perceived affiliation with those that died will be highly variable—causing some students to feel that their grief is more legitimate or intense than that of peers and even lead them to question if others are grieving out of proportion to what they “should” be feeling. Adult staff in the school may also have a wide variability in their connection with those that died.

After traumatic events (e.g., school shootings), members of the school community may demonstrate traumatic reactions that complicate, or at least add to, the grieving process. Crisis events can also uncover pre-existing trauma or loss [5] that may become a primary focus for the individual student or staff member, even if the prior events do not appear objectively similar in nature (e.g., the grief expressed by the friend of a student who was shot may remind a child about the distress he felt after his parents divorced several years prior; the death of a student may resurface feelings that a staff member had after a miscarriage many years prior).

Children and adolescents are being exposed to incidents of community violence at exceedingly high rates [6]. In communities characterized by high rates of community violence and resulting deaths, there may be the perception that somehow

the students “get used” to loss. This may occur because, in some of these situations, students learn that the adults are either unwilling or unable to protect them from further loss and too often are not forthcoming with needed support and assistance. As a result, children may conclude that there is little value in showing distress or seeking assistance from adults and may appear to some as unaffected. In reality, these children do not become accustomed or “desensitized” to these losses. Instead, each death may elicit the unresolved feelings and memories of prior losses, which increases the emotional burden carried by these children. In addition, poverty, discrimination, neighborhood disorganization, and loss of a belief in adults as protectors may increase children’s perception of vulnerability.

Those providing consultation to schools in the aftermath of a crisis event may be surprised at the wide breadth and intensity of reactions among students and staff, which may quickly overwhelm the school’s resources or capacity to respond effectively utilizing only regular school staff. Offers of assistance may follow quickly from members of the community and, in some high profile school crisis events, from individuals or groups from throughout the country and even from other countries. It becomes nearly impossible for schools to adequately evaluate and vet such offers of assistance in the immediate aftermath of the event and they often become guarded and more insular, accepting support only from those they know and trust. This underscores the benefit of community mental health providers establishing collaborative relationships with schools *prior* to a crisis event. Child mental health professionals already known and trusted by school leaders can play a valuable role in helping to assess the qualifications and likely benefits of accepting offers of help from professionals outside the school system and their known network of trusted advisers and consultants.

After a crisis event, it is increasingly common for mental health providers from other schools in the district, other districts, or the broader community to volunteer to provide on-site bereavement support in the immediate aftermath—often

for one or several days after the event. But in reality, grief is likely to evolve over time and children (and adults) become more able and willing to share their reactions and seek support long after volunteers have left the school and community. Child mental health professionals should be prepared to provide some level of support over a prolonged period of time, often in the form of training and other capacity building, consultation and support to mental health clinicians within the school, and technical assistance and consultation to school leadership.

Preparation of Staff to Support Grieving Students

Most teachers and other school professionals feel unprepared and apprehensive about reaching out to provide support to grieving students. Dyregrov et al. [7] interviewed a sample of teachers from primary and secondary schools and found that, although the school personnel had high levels of empathy and commitment towards grieving students, they expressed limited knowledge about how child bereavement affects school performance, concentration, and learning. They also expressed guilt for not doing more for bereaved children at school. Similar findings were found in a survey conducted in 2012 by the American Federation of Teachers, the New York Life Foundation, Tiller Inc., and Hart Research Associates [8]. More than 1200 educators reported that the single most important barrier preventing them from providing this support was insufficient training and/or professional development, with 93% reporting that they had never received any training on how to support grieving children during their education or subsequent professional development. This contrasts starkly to children's experience of loss—approximately 1 in 20 children experiences the death of a parent by the age of 16 years and approximately 9 in 10 report grieving the death of a close friend or family member by 18 years of age [9].

Children, like adults, will struggle with understanding and accepting the death and the impact it has on them and their family [1]. Parents, teachers, and other caring adults are often reluctant to talk with children who are grieving or even to raise the topic out of a fear of upsetting children by raising the topic or causing further distress by saying the “wrong thing.” Avoiding discussion is rarely helpful and often isolates children at a time when they are most in need of support and assistance. Children may also misinterpret silence by adults about the death as an indication that adults are unaware, unconcerned, or unwilling to be of assistance. Children may then conclude that the expression of their intense and complicated feelings is inappropriate, that adults do not feel that the person who died is worthy of being mourned, or that the relationship the children have with the deceased is not considered to be of sufficient value. The common reactions of shame or guilt experienced by grieving children can be intensified by this silence. Children may then model this avoidant behavior by not sharing their feelings for fear of upsetting their caregivers.

Preparation for Child Mental Health Professionals to Provide School Bereavement Consultation

Since the direct provision of bereavement services to children in a school is often not possible for child mental health professionals who are not employed or contracted by the school district, child mental health professionals should establish a relationship with local and regional schools *before* a crisis event so that they can provide guidance and training about how to best support grieving students and staff after an event. Ideally, training and professional development on this topic would be provided prior to a school incident or crisis; while staff may acutely appreciate the importance of such training after a crisis event involving deaths, their capacity to

learn the information and develop sufficient confidence in their skills is markedly diminished when they themselves are grieving or traumatized.

Establishing a collaborative relationship with a school or district prior to a crisis event allows the consultant to become aware of the distinct characteristics, history, and/or values of a school community. Schools differ significantly on a variety of factors including: the level of participation of families and school staff in school governance; resources available for support services; integration of mental health, wellness, and addiction services into normal operations; and sensitivity about different cultures served by the school. This knowledge can be critical in developing an effective recovery plan for the school or district, as well as providing effective bereavement support for individual students and staff.

There are a broad range of services that child mental health professionals can provide after a school crisis to assist grieving students and staff, including:

- Explaining how the experiences of grief and loss are common in school-age children and normalizing the range of reactions children may experience, such as guilt, shame, and anger [9].
- Providing school personnel with the information and skills necessary to support grieving children and their families, including:
 - How grief may be experienced by children at different developmental levels
 - How to address the needs of children with autism spectrum disorders, intellectual disability, depression, anxiety, and other mental health problems
 - How to help children identify, express, and cope with their feelings and reactions
 - How to offer appropriate explanations for sensitive situations, such as when a death is due to suicide (*Guidelines for Schools Responding to a Death by Suicide* that includes sample scripts for educators related to explaining suicide can be accessed at www.schoolcrisiscenter.org)

- Helping to establish norms about what school professionals can do to support grieving students including ways they can assist students in how they express and cope with feelings.
- Emphasizing the importance of all school professionals to work as a team to provide this support.
- Supporting the school administration's efforts to dedicate school resources to support grieving children.
- Advising on systems to provide coordinated and sustained recovery efforts.
- Implementing bereavement support services and groups within the school and identifying community bereavement organizations and camps as resources for children and their families. The National Alliance of Grieving Children (www.childrengrieve.org) and the Moyer Foundation (www.moyerfoundation.org) provide listings of local organizations offering bereavement services for children.
- Developing mechanisms for the identification, triage, and referral of students in need of additional mental health services beyond what can be offered in the school.
- Encouraging schools to maintain ongoing support for students throughout the grief process, including subsequent years in their school career and during times of transition, such as between grade levels or schools.
- Advising schools on how to provide outreach to families of grieving students to determine how best to provide mutual support to the students, while recognizing and addressing resistance that may be encountered.
- Ensuring that the unique bereavement support needs of staff are being addressed through such efforts as employee assistance programs, modifications in staff workload and supports as needed, and improvements to school climate and culture.
- Ensuring that school mental health providers (e.g., counselors, psychologists, and social workers) and support professionals (e.g., nurses who may see grieving students with somatic complaints) have the necessary training to identify and address the needs of students who are grieving or those experiencing related problems (e.g., post-traumatic

reactions, anxiety, depression, or suicidal ideation or intent) that are likely seen after a school crisis. This will likely include:

- How to support students feeling common, but strong, feelings and reactions such as guilt, shame, and anger, which can impede open discussion, acceptance of personal support and counseling services, and ultimate coping and adjustment [9]
- How to evaluate and respond to suicidal or homicidal ideation or intent, increased risk-taking behavior, or substance abuse
- Anticipating and addressing exacerbation of pre-existing mental health and substance use problems
- Identifying strategies to engage families that appear to be struggling or resistant to support
- Advising on issues related to commemoration and memorialization.

Academic Supports for Grieving Students

Children typically experience at least temporary academic challenges after the death of a close friend or family member. Some children may instead respond to a death by overachieving in school. The effect the loss has on learning may first appear weeks or even months later. Many bereaved children have been found to experience a reduction in school grades and an increase in school dropout rates [10] and teachers commonly perceive grieving students as struggling with learning, showing reduced achievement in tests, and experiencing learning setbacks [11]. The academic effect of bereavement may be prolonged and intermittent support may indeed be needed throughout children's school career [12].

Difficulty concentrating and distractibility, anxiety, depressed mood, and sleep difficulties may limit a student's learning capacity. Children with learning problems that predated the loss may experience a marked worsening in their academic performance.

Schools should offer academic supports *proactively* and modify school expectations and requirements as needed. A plan can be suggested in which the grieving child's caregivers and educators work together to identify the level of academic work that feels appropriate and achievable at a particular point of time in the recovery process. Ongoing monitoring should occur so that a balance between maintaining reasonable expectations and being ready to provide additional support and accommodation for grieving students is optimized. Although adaptations in workload and modifications of expectations are often needed, if academic standards are lowered dramatically and for an extended period, students may not be prepared for the workload the following year; if promoted without learning the essential facts and concepts of their grade, grieving students may be at a disadvantage the following year, when new teachers may be unaware of their losses or unwilling or unable to continue significantly lowered expectations. If instead children are held back a year, they may lose the affiliation of their peers who are promoted and the valuable support they provide.

Some helpful modifications of academic requirements might include:

- Change assignments: assignments can be adapted to better match grieving students' current ability to focus. For example, a student may be allowed to work on a project with a partner rather than individually; a student may be permitted to adapt a formal research paper into a more engaging assignment, such as an oral history project or a video; or a student may be permitted to defer an oral presentation and submit a written assignment instead.
- Change the focus or timing of a lesson: a literature class might choose a different book to discuss if the one originally scheduled describes a death similar to the one a student is currently grieving; a health class on the dangers of substance abuse might be postponed, or the grieving student excused, if he has just lost a sibling to a drug overdose.

- Reschedule or modify tests: immediately after a death, students might be exempted from some testing, or given modifications such as testing alone in a quiet location with extra time; scores obtained after the death might be omitted or weighted less in determining final grades.

School staff should work as a team to coordinate services and support for students. Teachers, coaches, and those overseeing other extracurricular activities should communicate with each other to make sure the collective work and responsibilities of grieving students are consistent with the students' current capacity. Students may also be experiencing disruptions at home such as altered or chaotic schedules or routines or surviving family members' grief that may create an environment that compromises the students' ability to complete homework or practice a sport or musical instrument. The school mental health providers may be able to share insights about strategies for dealing with reactions or approaches used by families to promote coping and adaptation, while teachers and other school staff can share observations about current functioning in school that they have observed. Together, they can work collaboratively to promote support and minimize unnecessary additional stressors.

Management of Grief Triggers

Common reactions of a grieving student such as outbursts of anger or sadness and uncontrollable crying can result in embarrassment when expressed in a classroom. After a significant loss, students may unexpectedly encounter situations or comments that remind them of the person who has died—the student may hear a song that the person liked in music class; the teacher may mention a city in social studies class where the student and the deceased friend or family member had spent a special time; a discussion of graduation may remind a student of the absence of a friend. These unexpected reminders can cause a temporary resurgence of some of the intense feelings of grief and may be

associated with a feeling of being out of control. These grief triggers are most common in the first few months after the death, but may happen at any time.

An important aspect of helping grieving students feel safe at school can involve preparing children for grief triggers and planning how they can be managed (similar approaches can be used for addressing trauma triggers) [9]. Students should be assured that grief triggers are common and that while intense, the immediate experience will pass and cause less stress than the worry about their occurrence. A plan for how to handle grief triggers that may occur may include the following:

- Identify a location where the student can go if a grief trigger were to occur in class—this may be the office of a counselor, social worker, or nurse, or a quiet location such as the library or the back of a classroom across the hall where the student can temporarily escape any pressure, demands, or unwanted scrutiny by peers, until the student is ready to return and re-engage in the class.
- Establish a procedure for children to leave the classroom if they are feeling overwhelmed. Knowing they can leave makes them less likely to need to leave. Most students will never need to take advantage of this opportunity but they will appreciate the option. Simple communications such as hand signals, a brief note, or a key phrase that do not draw attention from peers might serve as an appropriate notice to a teacher. Older students can be provided more independence while younger children will need the safety of an attending adult.
- Identify an adult that the student can speak to when feeling upset or wishing to talk.
- Allow the child to call a parent or family member when needed.

School staff can work with grieving students and their families to anticipate and minimize triggers to the extent possible, such as being aware of important anniversaries (of the death, birthdates of the deceased, etc.), special occasions (e.g., Father's or Mother's Day, Thanksgiving, or other holidays),

important transitions (e.g., graduation, starting at a new school, moving), and lost opportunities (e.g., vacations, performances, sports events, father-daughter dances). Additional support and invitations to talk or share feelings can be made around these times and accommodations made to assignments. For example, a teacher may introduce an activity focused on writing a poem to students' fathers on Father's Day by acknowledging that some students may not currently have a father who is alive or living with them and inviting them to either conduct the exercise based on the memory of their father or to choose another important adult male in their life to honor. Such an introduction is not only sensitive to grieving students, but also acknowledges that students may have fathers who are deployed, incarcerated, living out of state, unknown, or otherwise not present.

Peer Engagement

Most children will want to be supportive to peers who are grieving, but often have limited knowledge and experience about how to support a peer who is grieving. Like adults, they may be afraid to say or do the wrong thing. The death may also create uncertainty about the vulnerability of their own family and they may distance themselves from the grieving student to cope with their own anxiety. Children who are uninformed or unprepared may unintentionally isolate or tease a classmate after a death. This can worsen the isolation grieving students already feel. Cain and Lafreniere [13] found in their sample of 35 parentally bereaved children aged 6–15 that 20% “*experienced direct, raw taunting about their loss.*” Many of the bereaved children reported that peers—friends even—seemed to avoid them and some peers made fun of the bereaved child's grief or mode of coping with the loss.

Teachers can help prepare classmates so they are better able to support grieving students. Child mental health professionals can provide guidance to teachers about how best to do this. Especially after a school crisis, where the teachers

themselves may be grieving and/or dealing with associated trauma, direct assistance in the classroom may be indicated. The goals of a classroom discussion may include:

- Provide information and correct misinformation and misunderstandings. The students should be helped to understand, at a very basic level, what has happened, without providing graphic or unnecessary details. They will be less likely to burden a grieving peer in the immediate aftermath of a death with repetitive questions if adults have already provided sufficient information.
- Give students an opportunity to ask questions. Students are likely to have questions about what death is and the effect it has on children and their families. They will want to know how to be helpful to someone who is grieving.
- Offer concrete advice and practical suggestions. For example, talk about ways to start a conversation with someone who is grieving. Discuss helpful things to say, and what not to say. Generate some ideas of how to be supportive to a grieving student, such as offering to sit with the student during lunch or recess or taking the initiative to generate a conversation while respecting when the student wishes to be quiet or alone.
- Provide a safe environment for all students to share thoughts and feelings. Invite students to talk individually about their own losses or the fears they may have about someone in their own life dying. Let them know about resources in the school for additional support and encourage them to turn to trusted adults in their personal life, especially their parents/guardians, for further discussion.
- Send home information to families of students in the class about the grief process and how they can help their own child better understand the impact of loss and cope with the school crisis (e.g., *After a Loved One Dies: How Children Grieve and How Parents and Other Adults Can Support Them* which can be downloaded at www.grieving-students.org or ordered at no charge at <http://newyorklifestore.com/nyl2>).

Funeral Attendance

School staff may be the only professionals that communicate with families after a death—but prior to the funeral—that are in the position to offer advice related to the advisability of funeral attendance by children. Children often benefit from participating in funerals, wakes, and other rituals after the death of close friends or family members [9]. These ritualized mourning practices provide students with a structured opportunity to grieve in the presence of family and friends while receiving their support and, as appropriate to the family, solace from their spiritual beliefs. It is generally helpful to offer children the opportunity to participate in wakes, funerals, or memorial services, to the extent they wish. When possible, an adult familiar to the grieving child, but someone who is not personally grieving (after the death of a family member, this could be a member of the school staff), can help mentor the child through the experience and moderate participation based on the child's reactions and preferences. Children who are excluded from memorial or funeral services often resent not being able to participate in a meaningful activity involving someone they care deeply about and may wonder what is so terrible that is being done to the loved one that it is not suitable for them to view. Basic information about what to expect during the funeral, wake, or other memorial event should be communicated to children, including how people may behave (e.g., while important to remain respectful and generally quiet, people will likely be talking softly; there may be many who cry while others will instead be quiet; some may choose to tell funny stories about the individual which may elicit laughter, etc.). Children, however, should not be forced or coerced to participate in particular rituals or to attend the funeral or wake. After a school crisis that involves deaths of members of the school community, students may feel significant social pressure to attend or participate in various ways. Messages should be clear to students and staff that how people grieve is a personal choice and that individuals should decide whether they wish to attend and how they may wish to participate—

and that these personal decisions will be respected. Suitable alternative activities should be made readily available to students if the events occur during school time, including when the activities are school-wide and held within the school.

It is recommended that schools proactively review their policies related to student and staff participation in funerals and other memorial events to ensure that they address the following [1]:

- Policies should facilitate the attendance of interested students and staff at the funeral of someone close to them. If the funeral takes place during school hours, parental permission to attend is required. For young children, it may be most appropriate to ask parents to personally accompany their children to the services.
- When the death involves a member of the school community, such as a student or staff member, consideration should be given to hiring substitute teachers and making arrangements for coverage of other personnel so that they are able to attend if they desire.
- If significant numbers of students are attending off-site funerals or other memorial events, consideration should be given to having school staff present to provide informal support to students.
- Acceptable alternative activities should be provided for students who prefer to stay at school.
- After some school crisis events, more students and staff may wish to attend than can be readily accommodated. In some circumstances, the family can be asked about moving the services to a larger location or planning additional commemoration and memorial activities outside school hours. The use of school buildings for funeral services, especially if the body of the deceased will be present, is not advisable. This may establish difficult associations with that space for students and staff in the future. The exception would be schools with religious affiliations that have an on-site place for worship, such as a chapel or temple. Schools may also wish to hold separate commemorative events at school distinct from services planned by the

family and intended for relatives and family friends. Family members can be invited to attend such school events, but the focus of these school events would be to meet the needs of the school community.

Meaning Making Through Commemorative and Memorialization Activities

Memorial and commemorative activities can assist in the recovery process because they provide an opportunity for survivors to reflect on the meaning of their losses, especially since death can challenge many of the beliefs or assumptions they previously used to guide their lives. Children can find support through memorialization and commemoration if the focus of the activity is developmentally appropriate and relevant to the students and the event is planned at a time when the child is emotionally ready [1]. At times, schools may initiate plans for commemoration literally within minutes of a crisis event. Such premature commemoration may signal to students and staff that the focus should be on creating positive long-term tributes rather than expressions of acute grief and the sharing of current concerns.

Child mental health professionals can assist schools in the planning of memorial and commemorative activities to ensure that the events help students in the following ways:

- Communicate at a public level their connection and attachment to the individual(s) who died
- Express and cope with strong feelings that may otherwise seem overwhelming or difficult to deal with on their own
- Realize that they are not alone in having strong feelings
- Draw on the support of peers and adults in the school community
- Begin to find some meaning in the loss
- Feel reconnected to beliefs that may have been shaken by the experience
- Learn coping strategies that have worked for others, and share their own coping approaches with peers

What is actually planned for a memorial or commemorative activity is far less critical than how the school goes about the planning process [1]. In many ways, the discussion about what the students wish to remember about the individual(s) who died and the meaning that this loss has to them personally is more critical than actual participation in the memorial or commemorative event. Students in the school, including the grieving students, should play a central role in planning events to the extent they feel able and desire to do so. This ensures that the activities are relevant to students' interests and responsive to their needs. A commemorative or memorial event planned by adults for children is likely to be helpful to the adults rather than the children. When children plan and take part in these activities they increase their sense of control at a time when they may struggle with feeling powerless and vulnerable after a crisis event.

Thoughtful memorial responses should evolve out of an ongoing discussion with students and staff that were impacted by the crisis about how they most wish to remember the lives of the victims. Often these discussions result in symbolic activities that do not require the raising of any funds and are more meaningful and expressive than formal, traditional means of memorializations (such as placement of plaques in the hallway, dedication of the yearbook, or planting a tree). Practical considerations of formal and permanent memorials should be carefully considered. For example, the death of a tree that is planted as a memorial to a member of the school community may cause subsequent distress; memorial gardens may pose a challenge if school construction later requires that the site be displaced. Formal memorials may also inadvertently establish a precedent. At the time of subsequent deaths of students or staff, people may question why similar memorial activities are not instituted—for example, the friend of a child who dies of cancer may question why more attention was given to a child who died from sniper fire; classmates of a student who died by suicide or drug overdose may question why the death of their peer is not similarly acknowledged.

It should be anticipated that members of the school and broader community may have very different views about how best to memorialize individuals who died in a school crisis event. Family members and close friends may feel strongly that a prominent and permanent memorial is critical so that those who died are never forgotten; others may prefer to honor the individuals who died but discourage formal memorials that may serve as a traumatic reminders; and others who are less impacted may prefer to minimize ongoing attention to the event or the losses. A crisis event often leaves survivors feeling powerless and vulnerable and they may try to regain some sense of control by strongly advocating for how they wish to memorialize those who died in the event. The resulting difference of opinion coupled with associated strong emotions can result in a high degree of conflict among members of the school and broader community. These adversarial interactions often increase the anxiety of children and adolescents who look to adults for security and consistency at a time of instability. Child mental health professionals may provide valuable assistance in helping people understand the ultimate goal of such memorialization efforts (i.e., to allow survivors to honor and remember those who have died in a way that is helpful for the adjustment of survivors), acknowledge that members of the community have different and often competing legitimate personal preferences, and facilitate respectful discussion that aims to achieve a solution that meets the needs of the majority of the school community. It is important, though, to remember that the primary audience for a school response is the students and school staff and their needs should have priority above others in the broader community. This does not preclude the broader community from developing their own independent memorials.

The goal of commemoration or memorialization is to remember what was lost and what survivors wish to preserve, rather than to remember the moment or method of the loss. The intent is not to memorialize the tragic event, as much as what was lost as a result of the tragedy or subsequently learned from the experience. As such, traumatic reminders

should be minimized (e.g., a moment of silence at a commemorative activity at the 1 year anniversary need not coincide with the moment that a bomb detonated or shooting began; permanent memorials should not aim to recreate images associated with the disaster).

Spontaneous Memorials

When schools do not engage students in the process of planning for commemorative and memorial activities, there is a greater risk that spontaneous, informal memorials will appear in the school or within the community at a location associated with the individual(s) who died (e.g., school locker) or at the site of the death. These might include collections of notes, flowers, photos, stuffed animals, or something associated with the interests of the deceased.

Often, these spontaneous memorials appear almost immediately after notification of the death occurs. When this happens, the school should respect this expression of grief by the children but communicate that these memorial displays will be managed on the school property so that the bereavement needs of the entire school community are respected. For many children, these memorials may serve as grief triggers when they want to focus on other aspects of the school experience. The following issues can be incorporated into guidelines by schools on how to address spontaneous memorials [1]:

- Temporary memorials should generally not be in locations where all students are obligated to pass regularly, such as cafeterias or main hallways. Locations should also not be so isolated that it prevents regular monitoring by school staff. If necessary, work with students to relocate a temporary memorial to another site.
- The memorial may not block exits, hallways, or access to student lockers.
- No permanent writing on property (e.g., on lockers of deceased students) is permitted.

- Objects left at the memorial cannot be perishable or pose a risk to safety (e.g., lit candles, alcoholic beverages).
- Inappropriate material, whether written comments or objects, should be removed promptly.
- Students will be included in the discussion about how long such a memorial will be left in place (generally, a few days to a week) and whether the collected items will be delivered to the family of the deceased or donated elsewhere.
- Times during the school day when students are permitted to visit the memorial.

Spontaneous memorials constructed in the community can be problematic, especially if they are placed in dangerous locations, such as busy intersections or railroad tracks where the student(s) died. These also may become sites for future risk-taking behaviors, including substance abuse. An increasing number of memorials are also being posted on the internet where mourners post comments and sometimes engage in an imaginary dialogue with the deceased. The child mental health professionals can advise the school counseling staff about ways they can discuss with students how these memorials can both support and complicate the mourning process.

Professional Self-Care

School staff often feel uncomfortable providing support for grieving students because they feel untrained and unprepared in addressing the needs of grieving children. Grieving and emotionally vulnerable children can trigger a range of reactions in school staff. It is distressing to witness the distress expressed by children as they grieve, especially when the adults know and care about the students, as teachers and other school staff do. The strong emotions and expressions of grief may also remind adults of losses and trauma in their own lives [1]. After a school crisis event, the staff have many of the same feelings and reactions as the students and in many situations may be more directly impacted and grieving

more deeply. But the services provided in the aftermath of a school crisis are too often focused solely on the needs of the students and their families, and fail to address the full range of needs of the school staff. School mental health professionals may become overwhelmed by the sudden and prolonged increased need for their services to assist grieving students (and staff) and are at increased risk of compassion fatigue and vicarious traumatization in the aftermath of a school crisis. After a school crisis, child mental health professionals in the community can play a vital role in providing clinical supervision for school-based mental health providers, ensuring that mechanisms are in place to acknowledge, legitimize, and address the needs of grieving school staff, and assisting school leaders in addressing recovery efforts while also meeting the school leaders' professional self-care needs. Guidance about the importance of self-care and advice on how school staff can minimize compassion fatigue will help school staff feel less reluctant to engage grieving students [14, 15]. School staff can be advised to consider seeking additional support, beyond the informal support of their coworkers, when guilt, resentment, or personal grief is particularly strong or persistent, or when these or other feelings begin to interfere with personal or work life. The child mental health professionals can then assist with referral resources.

While planning for professional preparation of school staff, as well as response activities after a crisis, it is important to recognize and address the needs of all school staff. Educational support professionals (e.g., bus drivers, custodians, cafeteria workers, and office staff) play an important role in establishing a school climate that supports grieving children and in providing tangible and practical supports to students and staff. They too are deeply affected by school crisis events and may be overlooked in recovery efforts.

Similarly, it is important for child mental health professionals to be cognizant of the impact on themselves of responding to a school crisis event involving student or staff deaths. While this is a general issue that spans a range of services provided by child mental health professionals, some

unique features may be the sudden surge in needs in the aftermath of a crisis event, the reality that local child mental health professionals may have personal connections with grieving students or staff (e.g., their child may be a student at the school or they may have friends who have children, or are themselves, impacted by the event), and the recovery period is generally much longer than what is anticipated by the schools and communities that are impacted and even more so by the public at large.

When responding to a school crisis event, child mental health professionals may find that virtually every student and staff member has been impacted in some way and feelings related to their prior and concurrent losses and stressors may also resurface or become more pressing. Consultation is needed not only in terms of responding to the mental health needs of individuals and families. Disruptions in the relationships among members of the school community can strain friendships and working relationships and leaders may demonstrate resistance to advice or difficulty in planning an effective recovery. The consultant may be asked to assist with many decisions in the absence of definitive evidence and when all parties are distressed and at times overwhelmed. It therefore is important that consultants respond in teams of experienced colleagues who can assist each other with the response and recovery efforts and serve as a sounding board and advocate for professional self-care of each other.

Available Resources

The *National Center for School Crisis and Bereavement* (NCSCB), www.schoolcrisiscenter.org, established in 2005 (expanding a program established in 1991), aims to prepare school professionals to support children experiencing crisis and loss and promote an appreciation of the role that schools can play in supporting students, staff, and families at times of crisis and loss. Through collaborations with various organizations and agencies, the Center serves as a resource

for information, training materials, consultation services, and technical assistance. The NCSCB provides free on-call technical assistance and consultation to school systems, schools, and school professionals via a toll-free number (877-53-NCSCB (877-536-2722) or info@grievingstudents.org) to help address school crisis events and to assist schools in supporting grieving students. Free guidance documents and tools to respond to a school crisis event can be downloaded from the website.

The *Coalition to Support Grieving Students*, www.grievingstudents.org, is a collaboration of leading school-related professional organizations who have come together to develop and distribute a range of professional development resources that are freely available to the public. The coalition created a free school practitioner-oriented website with over 20 video training modules on topics ranging from how to talk with grieving students to responding to a school crisis event. Module summaries, handouts, reference materials, and guidance documents providing step-by-step practical advice are available for free download. Members of the coalition include organizations representing classroom educators; superintendents, principals, and other school leaders; school mental health and student support personnel including counselors, psychologists, and social workers; school nurses; pediatricians; NCSCB (which coordinates the coalition); and the New York Life Foundation.

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Chapter 11

Hospice Services and Grief Support Groups

Angela R. Ghesquiere

Hospice provides medical care, pain management, and emotional and spiritual support for people with a life-limiting illness or injury. To be eligible for hospice care, a patient must have a life expectancy of 6 months or less. Upon admission to hospice, the focus of care shifts from curative and life-prolonging treatment to comfort-focused and palliative care [1]. Hospice care is typically delivered at home, but can also be provided at dedicated inpatient facilities or in nursing homes [1]. Care is delivered by an interdisciplinary team, which can consist of the patient's personal physician, a hospice physician or medical director, nurses, hospice aides, social workers, bereavement counselors, clergy or other spiritual counselors, trained volunteers, and speech, physical, and occupational therapists, if needed [1].

The availability of hospice support in the United States has expanded greatly in recent years. The first US hospice was opened in 1974, and the number of hospices increased from 5150 in 2010 to 6100 in 2014 [1]. In 2014, about 1.2 million patients died while in hospice care [1], representing

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about 45% of all US deaths [2]. In 2014, 36.6% of those admitted to hospice had cancer diagnoses; dementia (14.8%), heart disease (14.7%), and lung disease (9.3%) were also fairly common [1]. While hospices vary greatly in size, about 46% provide care for more than 100 patients a day [1]. Most (59.1%) are free-standing, but 19.6% are part of a hospital system, 16.3% are part of a home health agency, and 5.0% are part of a nursing home [1].

As with any death, those who lose a loved one in hospice commonly experience grief, loneliness, anxiety, or pervasive feelings of sadness [3]. Bereavement can cause great emotional pain and affect daily life routines [4]. Bereavement in all contexts is associated with a range of negative outcomes, including increased occurrence of physical symptoms (e.g., headaches, chest pain), higher rates of disability, higher rates of physical pain, weight loss, and increased mortality risk in widowed men [5].

Loss of a loved one in hospice is typically expected, and quality of care around the death differs from that in other settings. Although the relationship between bereavement and the circumstances of a loved one's death is complex [6], losing a loved one to a chronic illness appears to be associated with better bereavement outcomes than sudden loss [5]. It has been theorized that a more prolonged dying period facilitates acceptance of the reality of their impending loss and allows the bereaved to work through some of the pain of the loss before it occurs [7]. The unique informal caregiver role in hospice care appears to facilitate this process—typically, a family member or friend serves as the primary caregiver and works with multidisciplinary hospice care teams to support the terminally ill individual. Indeed, one of hospice's guiding principles of hospice is that both the patient and their family are the unit of care. Consistent with this principle, services for informal caregivers, both before and following the patient's death, are considered key components of hospice care [1].

Research has found that the use of hospice care is correlated with lower fear of death in patients, which is in turn associated with more positive bereavement outcomes in

caregivers [8]. Work has also found that situations in which the deceased experienced a painful death were associated with high levels of anxiety, yearning, and intrusive thoughts in the bereaved, while perceptions of physician negligence were associated with high level of anger in the bereaved [9]. These findings imply that quality end-of-life care which manages pain (a key goal of hospice care) can improve bereavement outcomes in caregivers. Moreover, a study of caregivers who participated in a hospice program prior to the death showed that they had decreased feelings of guilt, dependency, loss of control, despair, numbness, shock, and disbelief after the death [10]. Hospice care therefore appears to have multiple benefits to caregivers post-bereavement.

Hospice and Bereavement Services

In 1982, the Tax Equity and Fiscal Responsibility Act (TEFRA) established a Medicare Hospice Benefit, with Medicare remaining the primary payer for hospice services in the United States [1]. Regulations for Medicare specifically require hospices to conduct an initial and ongoing bereavement risk assessment of the patient's primary caregivers, incorporate these assessments into the plan of care, provide at least one follow-up post-death contact with family or friend caregivers, and have an organized program established to provide bereavement services to caregivers for up to a year following the patient's death [11]. Medicare defines bereavement counseling as emotional, psychosocial, and spiritual support and services provided before and after the death of the patient to assist with issues related to grief, loss, and adjustment [11].

Yet though Medicare-certified hospice programs are required to provide support to bereaved caregivers, services are not separately billable [12, 13], resulting in limited financial incentives to provide more than a minimal level of bereavement care. Historically, bereavement programs have therefore been seen as the "poor stepchild" of hospice services [13]. A 2003 survey of US hospice found that in 65% of

hospices, bereavement services accounted for less than 5% of the budget, while bereavement services accounted for 5–10% of the budget in 27% of hospices. Only 8% reported that more than 10% of their budget went to bereavement services. The same survey also identified lack of sufficient staff time, funding pressures, and lack of personnel as key obstacles to bereavement service delivery [14].

In addition, Medicare reimbursement is not tied to the level or quality of services provided to caregivers and the specific services provided are left to the discretion of each hospice. Though the National Hospice and Palliative Care Organization has suggested guidelines for bereavement practice in its standards of practice for hospice programs [15], there are no federal standards regarding the types of services that must be offered [12]. As a result, there is great variability in bereavement services provision, with some hospice providing minimal services and others providing more comprehensive services [12].

Little is known about the scope and intensity of hospice bereavement services provided to family and friend caregivers, though a few large surveys have examined hospice bereavement practices. The first of these was conducted nationally in 1986 [13] and then replicated nationally in 2002 [14]. Most recent was a 2008–2009 national hospice survey [16, 17]. Statewide surveys have been conducted in California [12] and Ohio [18]. These surveys indicate that almost all hospices (over 95%) offer bereavement support services [16, 17] and that bereavement services were typically in place almost as long as the hospice was in existence [14]. Types of services consistently offered include telephone calls to the bereaved, condolence letters sent at the time of the death and at anniversaries, informational materials on the typical grieving process and how to cope with grief, home visits by bereavement staff, grief workshops and grief support groups, individual counseling [12, 14–16]. Less intensive services are most common; in the most recent national survey, which surveyed 591 hospices, 98% of hospices offered telephone calls, 98% sent cards at the time of death and/or anniversary of the

death, 94% provided brochures or other educational materials about grief, 93% offered home visits, 88% provided memorial services, 79% provided grief support groups, 71% provided individual therapy, and 51% provided group therapy [16]. Creative grief groups are also common; here, creative artistic activities such as art, drama, writing, creating a collage, and making music are used to help express and process grief in a group setting [19].

Staffing of bereavement services is varied, though social workers are most often involved. In the 2003 national survey, those involved in coordinating bereavement services were most likely to have a background in social work (44%), followed by “mixed disciplines” (15%). “Mixed disciplines” included a combination of social work, religion, counseling, psychology, or nursing. Similarly, the California survey found that bereavement staff were typically M.S.W.s (29%) followed by clergy (19%) [12].

In large part because of the limited funding for bereavement services, staff size tends to be small. While national surveys have found that the large majority of individuals responsible for coordination of bereavement services (98%) were salaried at some level [14], only 33% of hospices had a full-time salaried position for a bereavement coordinator [13, 14]. Moreover, most hospices (62%) had only one bereavement staff person, with only 12% of them having more than three bereavement staff [14]. Understaffing may increase reliance on volunteers and the California survey found that volunteers accounted for almost a quarter of bereavement program staff [12].

There also appears to be significant variation in services provided by hospice size [12, 16]. For example, the California survey found that large hospices were more likely than small hospices to offer grief support groups (51% vs. 29%) and volunteer visits (89% vs. 75%) [12]. The most recent national survey found that hospices providing care to more than 50 patients per day were significantly more likely than the hospices with fewer than 20 patients per day to provide comprehensive bereavement services, even after adjusting for other hospice characteristics [16].

Grief Support Groups in Hospice

Many types of grief support groups are offered in hospice settings, ranging from groups open to any family member or those focused on specific types of loss (e.g., partner loss, child loss) or populations (e.g., gay men, older women). Groups may be open to new members each session, or closed, and may have a set number of sessions or be offered continuously [20]. Typically, grief support group activities include sharing one's bereavement experiences, particularly their feelings about the loss, sharing pictures and stories about the deceased, and education about the grieving process [20]. Online grief support groups, using message boards, email groups, or chat rooms, are also increasingly common [21], though they have not been well studied among caregivers of hospice patients.

Regardless of their structure, grief groups are theorized to be effective by instilling hope, in part by observing others who are progressing. Groups also assist in enhancing universality, showing people that they are not alone in their feelings. Groups can also offer education about the grieving process that can help clients know what to expect from their grief. Groups can also enhance feelings of altruism by allowing them to give others in the group. Groups can also assist in learning more ways to effectively communicate about one's loss, helping further the grief process. In addition, group members and the therapist can model effective ways to grieve. Further, groups can offer a sense of cohesiveness and self-acceptance [20, 22]. In keeping with these intentions, identified reasons that people join grief support groups include a need to share their grief with people who have similar experiences [23, 24], to receive emotional support, and to seek relief from feelings of distress and isolation [24, 25].

Grief support groups have some evidence of efficacy; for example, parents who attended a grief support group for child loss were significantly more likely to find meaning in those loss than parents who did not attend groups [26]. Groups appear to be particularly helpful to those lacking

other forms of social support [24, 27]. Some qualitative research has also been conducted on why hospice grief support group attendees found groups helpful. Interviews with group attendees indicated multiple beneficial aspects including being able to share their experience, getting to be with people with similar experiences, being reassured that they are not alone, being reassured not to fear their feelings, and having the opportunity to say things that they could not say to family and friends. Participants also reported that their understanding of grief changed through attending the group [28]. Another study found that those attending groups sought normalization of their experience, validation, healing, community, and an opportunity for sharing. The opportunity to mourn with others in similar situations and education on the grief process were also desired [23]. Despite these promising data, much more research is however needed on the efficacy of grief support groups in hospice settings.

Mental Health Disorders in Bereaved Caregivers in Hospice Settings

Though most family and friend caregivers of deceased hospice patients recover from initial reactions of acute grief and return to pre-loss functioning within about 6 months of the death [29], a sizable minority will develop bereavement-related mental health disorders. Complicated Grief (CG) and depression are among the most common. Similarly to other chapters, despite slight differences in diagnostic criteria, we will assume that CG, prolonged grief disorder, and persistent complex bereavement disorder are referring to the same condition. CG is characterized by symptoms of reactive distress to death (e.g., disbelief or bitterness) and disruption in social relationships or identity [30], while depression is characterized by low mood and loss of interest in usual activities [30]. About 13% of family members of deceased hospice patients experience depression and approximately 11% experience CG [31, 32].

Depression and CG are both associated with a number of negative outcomes, including chronic functional impairment, hypertension, smoking, sleep impairment, and suicidal ideation [5, 33–37]. Studies have identified predictors of psychological distress in hospice caregivers to include younger age, symptoms of depression before the death, and lower satisfaction with social support [32].

Hospices are uniquely positioned to screen for both CG and bereavement-related depression because they provide care prior to and during the patient's death. As noted above, hospices are required to do risk assessments for a range of poor bereavement outcomes, including psychological distress, and the 2002 national survey found that 92% of hospices surveyed did so [14]. The 2008–2009 national hospice survey found that 92% screen family or friend caregivers members for depression and 97% provide screening for CG at some point after the hospice patient's admission [16, 17, 38]. However, no data could be identified on the types of screening conducted. Although well-validated screens, including the Inventory of Complicated Grief [35] and the Patient-Health Questionnaire-9 [39], can accurately identify bereavement-related mental health disorders, their use in hospice is unknown.

Hospices also appear to offer some treatment for bereavement-related mental health disorders, with the most recent national survey finding that 71% of hospices provided individual bereavement therapy, 51% provided group therapy, while 79% provided either group or individual therapy [16, 38]. As is the case with all bereavement services, hospice size was significantly associated with services, with the hospices with largest patient volumes most likely to provide screening and access to bereavement therapy [16, 38]. However, no data is available on whether therapy addressed CG or depression in particular. Effective individual and group psychotherapeutic treatments for both CG and bereavement-related depression have been developed and piloted, including Shear et al.'s cognitive-behavioral "Complicated Grief Treatment" (CGT) and

Behavioral Activation (for depression) have been tested in randomized clinical trials and found to be effective [40, 41]. Shear's treatment is 16 sessions long and is based on exposure treatment for post-traumatic stress disorder; treatment activities include retelling the story of the death in the present tense and confronting reminders of the loss that one may have been avoiding. Chapter 13 describes in more detail CGT, and cognitive behavioral approaches to treating CG. Behavioral activation targets symptoms of depression and mainly involves scheduling activities to help the bereaved individual reengage in their daily lives. No studies appear to have examined whether these treatments are used in hospice, however.

Bereavement Service Utilization in Hospice

Limited research has examined the extent to which family and friend caregivers take advantage of hospice bereavement services offered. However, a recent study analyzing deidentified clinical and self-report data on 6160 hospice family and friend caregivers in Colorado [42] reported that in total, 25% of them used either group or individual hospice bereavement services, while 5% used both. In unadjusted analyses, caregivers considered by the hospice to be at risk for a range of negative bereavement outcomes were more likely than those considered low risk to use both individual and group counseling; 52% of the at-risk used services, compared to only 18% of those with low risk. Risk level remained associated with service use, even when controlling for age of the deceased, loss type, and caregiver gender. In adjusted analyses conducted only among at-risk caregiver, factors associated with higher service use included female gender and younger age of the deceased. Those who lost a child were least likely to use services. Bereavement services appear to be reaching many of those in greatest need, though men and those losing older loved ones appear to require additional attention.

Outcomes of Hospice Bereavement Services and Hospice-Specific Innovative Approaches

As noted above, participation in hospice itself has been associated with positive outcomes in bereaved family and friend caregivers. Evaluations of the general quality of hospice services provided to both patients and caregivers have included measures of multiple components of hospice service delivery [28]. Family and friend caregiver satisfaction appeared to be highest when caregivers were informed regularly about the patient's condition, when they felt the team provided them with accurate information about the patient's treatment, when they felt the hospice team was providing their desired amount of emotional support before the death, and when they could identify one nurse as being in charge of the patient's care [28]. However, more work is needed on the impact of hospice participation on caregiver outcomes.

Limited data is available on how hospices examine bereavement outcomes, and there appears to be considerable variability by hospice. In the 2002 national survey of hospices, 78% indicated that their hospice collected bereavement data. The most data collected was client satisfaction surveys (57%), followed by grief support group attendance (38%), number of contacts with clients (26%), number of clients receiving services (13%), evaluations of grief support groups (12%), and annual surveys of bereavement services (8%) [14]. However, though often collect satisfaction data with bereavement services [18], rates have not been widely reported.

A few innovative hospice bereavement programs have been reported in the literature, including specialized support groups for grieving children [43], grief support groups offered by hospice in community-settings [44], and a creative arts group [19], with evidence of positive outcomes. However, bereavement service outcomes have not been examined on a large scale. New interventions are also being developed for hospice settings. For example, Caserta, Lund, Utz, and Tabler have developed a "Living After Loss" intervention [45]. The approach is based on the Dual Process Model (DPM), which

posits that as individuals adapt to loss, they benefit by oscillating between two coping processes: Loss-orientation (LO) involves coping with the effects of loss itself, which typically encompasses engaging in grief work, cognitive processes and ruminations in attempts to make sense of the loss, and reconfiguring the nature of the bonds one has with the deceased [4]. Restoration-orientation (RO), on the other hand, involves coping with stress related to life changes resulting from the loss [4]. This might include taking on new responsibilities, mastering new skills to manage various tasks of daily living, doing self-care activities, and adjusting to a new role or identity without the deceased. Noting that most bereavement interventions are LO focused, Caserta, Lund, Utz, and Tabler developed both a group and individual treatment which incorporates both LO and RO features. They are currently examining the efficacy of the individual approach in hospice settings [45]. Additional evaluative efforts are needed to demonstrate the efficacy of hospice bereavement services beyond individual programs, however.

Recommendations

The existing literature points to several future directions in the hospice bereavement services. First, there is a need for additional funding for hospice bereavement services. Because Medicare does not provide bereavement service-specific funding, services are understaffed and underfunded. Lack of sufficient staff time, funding pressure, and lack of personnel have been identified in a national survey as key barriers to bereavement service provision [14]. Providing Medicare reimbursement specifically for bereavement services would greatly expand their reach and availability. Individual hospices might also seek alternative sources of funding for bereavement services, such as fundraisers or private donors. To increase the consistency of service provision, creation and enforcement of national standards for bereavement care could be implemented by the Centers for Medicare & Medicaid Services (CMS). Many CMS

standards are already in place for other components of hospice care to patients and could be expanded to bereavement care. Existing National Hospice and Palliative Care Organization standards could serve as a template [15]. There are also preliminary indications that these bereavement services may not adequately meet the individual needs of caregivers across language and ethnic groups; standards could include suggestions for tailoring to a range of cultural and ethnic groups [46].

Additional bereavement support could also be offered to family and friend caregivers pre-death. Bereavement staff typically has minimal contact with caregivers until after the hospice patient dies. A recent qualitative study with family and friend caregivers in hospice found that support around bereavement before the death was desired from providers, to help caregivers prepare for the death [47]. The authors suggest that training hospice staff to have conversations with family and friend caregivers about the imminent death and about grief, fears, and worries could facilitate anticipatory grieving among family and friends. The authors also argue that training of all hospice staff (not just bereavement staff) should develop communication skills around grief and loss, so that all staff gain confidence in addressing these sometimes uncomfortable topics with the caregiver. As staff become more comfortable, caregivers will be given additional opportunities to address the many feelings they are experiencing and expecting to experience, rather than focusing only on their practical caregiving tasks. In addition, hospice staff members with whom caregivers are regularly in contact before the death, such as social workers, could provide workbooks or worksheets that encourage the caregiver to engage in anticipatory bereavement [47].

Barriers to attending grief support groups have also been identified, which could be addressed in efforts to increase bereavement service utilization. One study [23] found that a sizable percentage of abereaved adult sample viewed attending a grief support group as a sign of weakness. Other bereaved adults in the study said that they were uncomfortable sharing feelings. Lack of awareness of the potential benefits was also a

barrier. Some were uncomfortable with the idea of groups, saying that they did not want to listen to others telling painful stories and crying, or that they found it too hard to tell their story. Some logistical barriers were mentioned as well, such as an inconvenient group location [23]. Similarly, the few identified studies of bereavement help-seeking in family and friend caregivers of hospice patients found that the primary reasons for not seeking help were not seeing the use in participating, not thinking that help was needed beyond existing family and friends, feeling that available services didn't fit needs or interests, and being uncomfortable talking to others about their problems [48, 49]. There is also an increasing interest in mind-body integrative approaches in the US [50]; bereavement support involving mindfulness meditation, guided imagery, aromatherapy, and other mind-body techniques may increase perceived fit for some caregivers, and the acceptability, feasibility, and efficacy of these approaches for bereavement could be further studied in hospice settings.

Future efforts might address some of these barriers, with efforts to enhance perceived need and increase comfort level in discussing problems especially important. Previous studies of bereaved family members of hospice patients indicated that engagement efforts could focus on enhancing perceived need and decreasing stigma around bereavement service use [48, 49]. Several interventions have been developed to address these factors in older adults with depression (*e.g.*, [51–53]), and these potentially could be adapted for family and friend caregivers of hospice patients. Making groups available in a variety of locations, or perhaps even in group phone or webcam call, might address some of the logistical barriers. Bereavement staff could also do additional outreach to help increase awareness of bereavement services and their benefits; in a study of people who had lost a spouse in hospice, caregivers expressed that hospice could be more direct and assertive when offering bereavement services [47]. Some also wished that more structured outreach was in place, such as a set number of visits to process the death and talk about next steps [47].

Additional research is needed on hospice bereavement services, particularly on a national level for those at-risk for poor bereavement outcomes, such as family members with symptoms of CG or depression. Further research is needed on whether screening is evidence based, if group or individual therapy addresses CG and/or depression in particular, if any therapy provided for these conditions is evidence based, and whether family members with bereavement-related mental health disorders utilize available hospice services. If screening and treatment are not evidence based, future studies could train hospice bereavement care providers in the use of well-validated CG and depression measures [35, 39] and brief treatments [40, 41, 54, 55].

Overall, hospices have a high capacity to provide bereavement care to large portions of the bereaved and are more well positioned than many other service delivery system settings to do so. With further funding, standardization of services, greater attention to cultural and linguistic variability, efforts to overcome barriers to service access, and additional research efforts, the best possible outcomes for the many individuals who lose a loved one in hospice care can be assured.

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Chapter 12

Two Psychosocial Interventions for Complicated Grief: Review of Principles and Evidence Base

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Complicated grief (CG), also known as Persistent Complex Bereavement Disorder (PCBD) in the DSM-5, or Prolonged Grief Disorder (PGD), is a persistent, impairing response to the death of the loved one. While diagnostic criteria sets for CG, PCBD, and PGD slightly differ, in this chapter, we will assume that they refer to essentially the same condition, a bereavement-specific syndrome that reflects poor adjustment

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after the loss of a loved one (hereafter referred to as CG). Generally, this syndrome of CG includes core symptoms of yearning or longing for the deceased, emotional pain, sense of disbelief about the death, and preoccupation with the deceased and/or circumstances surrounding the death for more than 6 months [1] or in some criteria sets, 12 months [2], following the loss. Additionally, those with CG may experience bitterness or anger related to the loss, self-blame in relation to the death, excessive avoidance of reminders of the loss, difficulty trusting others, and feelings of loneliness or isolation [1]. Individuals with CG often believe that life is meaningless without their loved one and are reluctant to pursue interests or plan for the future. Frequently, they may desire to die to be with the deceased [1]. CG is distinct from major depression and post-traumatic stress disorder (PTSD) [3] and contributes to impairment above and beyond the effect of PTSD and depression [4]. Fortunately, CG is a treatable condition, with evidence-based treatments developed to specifically target its underlying symptoms and improve the well-being and clinical management of those who suffer from it. In this chapter, we will briefly review three cognitive and/or behavioral models of CG, describe two psychosocial interventions designed to target symptoms of CG, and review the evidence base for these interventions.

Theories of Complicated Grief

Three prominent theories—cognitive behavioral theory, dual-processing model of adaptive coping, and the attachment theory—have emerged to explain the phenomenology of CG.

Cognitive Behavioral Theory

From the perspective of cognitive behavioral theory, CG arises from an individual's inability to accept the loss of the loved

one, in tandem with maladaptive grief- and death-related interpretations and avoidant coping strategies [5]. Central to a cognitive behavioral framework is that psychopathology persists because of distorted, maladaptive interpretations of ambiguous or personally meaningful information and problematic behavior stemming from these biased appraisals, which are mutually reinforcing. In the case of CG, bereaved individuals make biased grief-related appraisals about themselves, the future, and their own reaction to the loss; and engage in avoidance behavior that impedes healthy coping with the loss. For example, individuals may feel they are to blame for the loss (e.g., *I could have stopped it if I had been there*), they have no purpose or sense of meaning without that person, or that they are not reacting normally to the loss (e.g., *If my grief diminishes that means I don't care about the person*). The loss of a loved one can also violate previously held beliefs about an individual's sense of self, their purpose, and their future [5, 6]. Consequently, loss may make the bereaved feel that their lives are meaningless without their loved one. They may also believe that experiencing any positive emotionality after the death is disrespectful to the memory of the deceased or renders the loss less significant. Thus, faulty global, negative, and internal cognitions about the self and their situation prevent those with CG from seeking out support or engaging in previously meaningful and often pleasurable behaviors (e.g., social activities, places, or hobbies associated with the deceased) that foster adjustment to the loss.

One specific model, Boelen's cognitive behavioral model of CG, further posits that bereaved individuals fail to adequately integrate information about the loss with existing, prior knowledge. A bereaved individual's initial schema of the deceased is that of a living individual characterized by elements of both a unique and shared past, and of possibilities of future interaction. While this schema is updated after the loss in most bereaved individuals, Boelen hypothesized that for those with CG information about the permanence of separation is not sufficiently integrated with older information about the relationship with the deceased [5, 6]. Essentially, for the individual with CG,

factual knowledge that separation is permanent does not get linked with information about the relationship with the deceased. Consequently, bereaved individuals with CG continue to experience grief as distinct (i.e., not integrated with other memories) and emotionally painful [5, 6]. From this cognitive behavioral perspective, this explains why bereaved individuals have difficulty accepting the loss as final, experience “*unrealness*” about the death, and continue to feel shock when they are reminded of the loss [5, 6]. Each reminder of the finality of the situation (e.g., that their loved one is permanently gone) is thus at odds with the cognitive framework of individuals with CG and consequently induces distress.

Accordingly, cognitive behavioral theories explain why individuals with CG engage in cognitive and behavioral avoidance of loss reminders that provoke this affective distress. Individuals with CG may avoid any objects, situations, or thoughts that may cause them to experience distress or confront the finality of the loss [5, 6]. In the context of grief, this behavioral avoidance includes avoiding people, places, situations, or things that are associated with the deceased. Additionally, individuals may also engage in cognitive avoidance, attempting not to think about the events surrounding the loss, which is negatively reinforcing and perpetuates the cycle of nonacceptance. Thus, cognitive behavioral theory-informed interventions may address an individual's reluctance to accept the loss, the faulty cognitions, and avoidance behaviors that prolong grief symptoms and perpetuate the syndrome.

Dual-Processing Model of Adaptive Coping

The dual-processing model of adaptive coping also emerged as a theory to understand the maladaptive patterns of prolonged grief that arise after the loss of a loved one [7]. Similar to the cognitive behavioral framework, the dual-processing model of adaptive coping acknowledges that persistent grief arises when bereaved individuals have difficulty accepting the loss of their loved ones, and develop maladaptive cognitive and behavioral

coping patterns. As with cognitive behavioral theory, avoidance of loss-related stressors is central to the dual-processing model of adaptive coping. Additionally, bereaved individuals are prone to avoid engaging in positive behaviors so that they may remain connected to the deceased [7, 8]. However, the theories diverge somewhat to the extent that the dual-processing model emphasizes the failure of coping mechanisms. The theory posits that typically, bereaved individuals experience an oscillation between two orientations: loss-orientation and restoration-orientation [7]. Most bereaved individuals spend time acknowledging the loss (e.g., attending a funeral, talking about the deceased with others, mourning the loss while looking at photos) and re-engaging in life without the deceased (e.g., attending a social gathering without the deceased, going to a restaurant that used to be enjoyed together, discarding items that belonged to the deceased). According to dual-processing model, CG develops due to a failure to alternate and find balance between these two orientations, such that bereaved individuals with CG spend their time focusing solely on the loss and fail to re-engage in positive life activities, which is thought to be motivated by a desire to remain connected to their lost loved one [7].

Attachment Theory

The attachment theory of CG emphasizes the attachment quality and style of the relationship between the bereaved and the deceased. Attachment theory developed from research on infant–mother attachment styles that were broadly characterized as either secure or insecure, depending on the infant’s response to the caregiver’s absence and subsequent ability of the caregiver to soothe the infant following a period of absence [9–11]. Adults, not just infants, are motivated to attach and adult attachments are also characterized by sexuality and caregiving systems, or the need to both care for others and be cared for [12]. Attachment is considered an intrinsic biological motivation

that when disrupted, either through separation or death of a loved one, leads to significant distress [10–12]. Hofer [13] theorized that loss of an attachment figure leads to a dysregulation of an individual's biological regulatory system, since that attachment figure plays a central role in their affective, attentional, and motivational processes [12]. Stated another way, when separation occurs (e.g., a mother temporarily leaves a toddler alone, or individual loses his/her spouse), the regulatory system becomes disrupted and is associated with emotional distress such as crying (affective process), difficulty attending to or concentrating on other stimuli (attentional process), and decreased or aimless involvement in other activity (motivational process). A basic premise of the theory is that loved ones (initially caregivers, but later intimate partners and even children) are viewed as "*safe havens*" or secure bases from which an individual explores and interacts with the world. That is to say, individuals with secure attachments function in the world autonomously, but return to the attachment figure as a source of support and comfort. As children age (and become capable of symbolic, cognitive processing), they develop mental representations of the attachment figure that can be a source of comfort even when physically separated.

Thus, whereas infant relationships require close physical proximity between mother and child, adult relationships rely more heavily on internalized representations (i.e., cognitive symbols, ideas, or images) of the attachment figure (e.g., parent, spouse, child) informed by the quality and functioning of the relationship [12, 13]. According to attachment theory of grief, the loss of an important attachment figure consequently changes an individual's sense of a security in the world and impacts interpersonal functioning [12]. From this perspective, the loss creates a mismatch between mental representations of the loved one and the sudden change in the bereaved person's relationship with the deceased, leaving the bereaved with a strong sense of yearning for the loved one and sense of disbelief over the loss [14]. Importantly, the loss of a close relationship impedes one's ability to construct a meaningful sense of

self without that person [8]. Thus, according to the attachment theory, the death of a loved one usually produces a state of traumatic loss and symptoms of acute grief that will evolve into a state of CG if an individual is unable to accept the reality of the death or reestablish their identity without that person [12].

In summary, three psychological theories of CG, cognitive behavioral theory, the dual-processing model of adaptive coping, and attachment theory, have emerged to describe the underpinnings and phenomenology of CG. Central to all three theories is the inability to accept the reality of the death, which consequently disrupts bereaved individuals with CG from maintaining a meaningful sense of self and purpose. Additionally, across all three theories, bereaved individuals with CG develop maladaptive coping strategies as a result of the loss, which has led researchers to develop evidence-based cognitive behavioral therapeutic interventions that directly target grief-related behavioral and cognitive avoidance and help individuals to re-engage in their life in meaningful ways. In the following section, we will review the principles and empirical evidence for two specific approaches based on these theories: cognitive behavioral therapy (CBT) and complicated grief treatment (CGT). Other therapeutic approaches, such as narrative therapy, similarly based on dual processing theory, is described in a separate chapter (Chap. 8).

Cognitive Behavioral Therapy Approaches

Principles

Guided by theory, cognitive behavioral therapy (CBT) for grief incorporates specific techniques to encourage acceptance of loss, modify maladaptive grief-related appraisals, and reduce avoidance. CBT has been delivered in group and individual settings and typically consists of 12 sessions. CBT consists of four core treatment interventions including psychoeducation, cognitive restructuring, exposure, and behavioral activation.

Psychoeducation

First, bereaved individuals receive psychoeducation about loss and the nature and symptoms of CG. The therapist reviews symptoms of CG, discusses the differences between acute and prolonged grief, and helps the patient understand the cognitive and behavioral factors that maintain grief. As with other CBT interventions, this phase allows patients to understand the nature and history of their distress and enables therapists to build credibility for the rationale for treatment while normalizing the patient's experience. In the context of grief, psychoeducation is an early step in helping patients begin to accept the loss as final [1].

Cognitive Restructuring

Cognitive restructuring is a series of techniques that includes identification, labeling, review of evidence, and reappraisal to directly target the faulty and negative cognitions that arise over the course of bereavement. The patient and therapist work collaboratively to identify the global, internal, and stable negative feelings about themselves and their situations that impede resolution of prolonged grief [1, 15, 16]. Commonly targeted thoughts in CBT for grief include inappropriate self-blame surrounding the death or deceased, belief that re-engaging in life or diminished acuity of grief would dishonor the deceased, or feelings of worthlessness or meaninglessness in life without the loved one [1].

Exposure Therapy

Another critical component of CBT for grief is the incorporation of exposure therapy into treatment sessions. A highly efficacious treatment for anxiety disorders and related conditions like PTSD, exposure therapies help individuals experience reductions in distress and disconfirm faulty beliefs about a situation (e.g., “*I can tolerate this feeling without going crazy*”) [17]. In the case of grief, the therapist works to

help the patient confront affectively salient reminders of the loss. This may include approaching situations that remind the patient of the deceased (e.g., looking at pictures of the deceased, discarding items of the deceased, visiting the cemetery) or completing written or spoken exposure narratives, in which patients are asked to repeatedly describe the loss of the loved one and recount circumstances of the death [1, 15, 18]. Through repetition, exposures help patients to accept the reality of the loss and reduce grief-related distress [1].

Behavioral Activation

Finally, some models of CBT for grief use components of behavioral activation modified for grief, to help patients re-engage in previously meaningful activities and enhance quality of life. In the context of grief, behavioral activation helps patients increase the frequency and breadth of their engagement in enjoyable and meaningful activities in everyday life [1, 19]. In addition to increasing engagement in pleasurable activities, previously enjoyed hobbies, and social activities, some CBT practitioners may facilitate behavioral activation for grief in the form of writing exercises, in which patients are asked to write a letter to a bereaved friend, to offer support, encouragement, and positive resolutions in the healing process [18].

Although there is not one universally adapted or published CBT treatment manual for acute grief or CG at the present time, and providers may vary their emphasis on particular strategies, CBT interventions are similar in their use of these techniques and shared the primary treatment goals of targeting faulty cognitions and behavioral avoidance that maintain pathological grief reactions and prolong nonacceptance of the loss.

Review of Outcome Studies

CBT has shown efficacy in reducing CG symptoms in comparison to waitlist controls or general supportive counseling.

In a randomized control trial (RCT) of an Internet-based CBT for CG, 55 bereaved individuals with CG were randomly assigned to either a waitlist control or CBT treatment group [18]. Wagner et al. [18] incorporated three CBT modules into the 5-week intervention, addressing core components of the cognitive behavioral model tailored to bereavement: exposure to bereavement cues, cognitive reappraisal, and restoration of goals. The treatment group improved significantly in comparison to the waitlist control, demonstrating reduced intrusive thoughts, avoidance, maladaptive behavior, and general psychopathology [18]. In a follow-up to this study, gains from CBT were maintained at 18-month follow-up [20].

In a stratified RCT, based on relationship to the deceased and type of death, Rosner et al. [21] compared CBT to a waitlist control. Fifty-one individuals with CG were randomly assigned to a waitlist control or integrative CBT. The treatment group received 20–25 sessions, which were divided into three parts: seven sessions that focused on stabilizing and motivating the patient to explore their individual grief situation; nine sessions devoted to teaching relaxation techniques and cognitive restructuring to address maladaptive views of self, the deceased, and the circumstances surrounding the loss; and four sessions focused on creating future goals while maintaining a healthy relationship to the deceased. Although this study did not incorporate exposure into the CBT intervention, the CBT treatment group had greater reductions in grief severity and depression symptoms relative to the waitlist control group [21]. In a follow-up study performed 1.5 years after treatment completion, Rosner et al. [22] found the treatment effects were stable over time and the general mental health improvements seen post-treatment were maintained among those in the CBT group.

In contrast to the two studies above, in which CBT was compared to inactive treatment groups (i.e., waitlist conditions), Boelen et al. [15] compared CBT to a nonspecific, but active treatment for CG to understand how a targeted

treatment, such as CBT, may perform relative to a general, supportive therapy. Fifty-four bereaved individuals with CG were randomly assigned to one of three conditions, two CBT conditions and one supportive counseling condition. Across all conditions, individuals completed 12 sessions of treatment. Both CBT conditions incorporated exposure therapy (ET) and cognitive restructuring (CR) into their sessions, but differed in the order in which the interventions were provided. One CBT condition led with 6 sessions of CR followed by 6 sessions of ET (CR + ET) and the other CBT condition led with 6 sessions of ET followed by 6 sessions of CR (ET + CR). Individuals in the third treatment group received 12 sessions of supportive counseling. Results from both completer and intent-to-treat analyses demonstrated that both CBT conditions led to greater reductions in psychopathology and CG symptoms than the SC condition [15]. Comparisons of the two CBT conditions suggested superiority of exposure relative to cognitive restructuring, such that ET+CR was more effective than CR+ET and that adding ET to CR led to greater improvement than adding CR to ET [15]. Another RCT further investigated how grief-focused exposure improves CBT in a randomized control trial of 80 bereaved individuals with CG [23]. All 80 individuals received 10 weekly, 2-h sessions of group CBT without exposure and then were randomized to receive four, additional 1-h individual sessions of exposure therapy to memories of the death (CBT + exposure) or four, additional 1-h supportive counseling sessions (CBT alone). Compared to CBT alone, CBT + exposure was more effective at reducing depressive symptoms, negative appraisals, and cognitive impairment [23]. Additionally, fewer patients met CG criteria at 6-month follow-up in the grief-focused CBT + exposure condition [23]. Together, these findings demonstrate efficacy of CBT and exposure therapy in particular for the treatment of CG. Although it is common for providers to be concerned that grief-focused exposures may lead to unnecessary provocation of distress, these findings underscore the importance of including exposure therapy to grief- and death-related cues.

Complicated Grief Treatment

Principles

Developed from the dual-processing model of adaptive coping and attachment theory, in which grief resolves optimally when attention is balanced between loss- and restoration-orientations, Complicated Grief Treatment (CGT) is a manualized bereavement-focused individual therapy that consists of 16 sessions designed specifically to treat the composite factors of CG [7, 24–26]. The rationale for treatment is that individuals with CG should receive both loss-focused (e.g., confrontation with reminders of the death) and restoration-focused (e.g., engagement in activities and goal setting) interventions. Additionally, informed by attachment and cognitive behavioral theories, a goal of the treatment is to simultaneously identify the patient's history and relationship with the deceased while addressing the complex emotions, and targeting maladaptive cognitive and behavioral patterns [1, 24]. As noted earlier, there is overlap between CG and other disorders, namely PTSD and major depressive disorder. Thus, CGT combines techniques derived from other treatment packages including prolonged exposure and interpersonal therapy (IPT) to treat symptoms such as intrusions, sadness, and social withdrawal [24]. CGT includes three phases of treatment, each of which uses different strategies to help individuals address their loss-focused distress and restoration-focused future goals [1].

Introductory Treatment Phase

In the introductory phase of treatment, there is emphasis on developing a companionship alliance between therapist and patient. Within this working alliance, individuals receive psychoeducation about CG and come to understand the differences between normal and complicated grief trajectories. In the first few sessions, patients learn about the rationale for the treatment strategies, such as the need to manage avoidance,

rumination, and excessively negative appraisals, the importance of creating positive memories, as well as the value of developing new goals [1, 24]. By learning about the rationale for the treatment strategies in tandem with this psychoeducation about CG, patients can begin to understand how specific aspects of the treatment target the foundations of their CG symptoms. With the therapist, patients also share details about their relationship with the deceased. During these first sessions, patients are taught the importance of processing the loss as well as restoring life functioning and purposeful engagement that may have halted after the death [1, 24]. Patients are also encouraged to bring a loved one into an early session to enable the therapist to learn more about the patient's grief and also facilitate grief-related social support for the patient.

Middle Treatment Phase

In the second phase of treatment, individuals address the maladaptive avoidance patterns and faulty cognitions surrounding the death, by participating in both situational and imaginal revisiting of the events surrounding the death and reminders of their loved one. Situational revisiting exercises take place outside of therapy sessions, in which bereaved individuals are asked to return to places they may have gone with their loved one or visit places that they may have avoided, like the cemetery. Imaginal revisiting is completed during therapy sessions, in which the patient describes in detail when they first learned about the death. The revisiting exercise is audiotaped, and then patients are asked to listen to the exercise at home to develop a new relationship with their experience surrounding the death [24].

Final Treatment Phase

The final phase is comprised of personalized goal-setting and plans for the future in order for the individual to lead a happy and healthy life during the final therapy sessions.

The therapist helps the patient to generate plans for moving toward the goals they want to achieve, and to develop concrete behavior changes each week to obtain those goals [1, 24]. At the end of a successful course of treatment, individuals have accepted the loss of their loved one, acknowledged the finality of loss, revised their life goals without the deceased, and re-engaged in meaningful activities.

Review of Outcome Studies

CGT has consistently shown efficacy reducing CG symptom severity across three RCTs. In the first study, Shear et al. [24] compared their novel grief-focused therapy, CGT to interpersonal therapy (IPT), to test their hypothesis that CGT leads to greater treatment response in bereaved individuals with CG than, non-grief-targeted psychotherapies. In this study, 95 bereaved individuals were recruited through a university-based research clinic as well as a satellite clinic in a low-income African-American community. Participants were randomly assigned to either 16 weekly sessions of CGT or IPT delivered over a 16–20-week period. Across treatment sites, randomization was stratified by type of death (e.g., violent or nonviolent). Although both IPT and CGT led to improvements in CG symptoms, CGT had both a higher response rate and a shorter response time when compared to IPT [24]. The first study to assess CGT, the authors concluded that although general therapies such as IPT may relieve some of the distress associated with the death of a loved one, CGT, a grief-targeted therapy, is an improved treatment model with greater and faster treatment response.

Shear et al. [26] again compared CGT to IPT in a second RCT, in which they examine CGT efficacy in an elderly bereaved population, a unique group with the highest prevalence of CG. Geriatric populations are more commonly exposed to loss of loved ones (see Chap. 6), yet many

clinicians are reluctant to implement exposure-based therapies with older individuals [26]. Shear and colleagues recruited 151 bereaved individuals 50 years or older and randomly assigned them to either CGT or IPT, an evidence-based treatment for depression. Bereaved individuals in both conditions received 16 individual weekly sessions, over the course of a 16–20-week period. Similar to findings of the previous study, both CGT and IPT produced reductions in CG symptoms. However, relative to IPT, CGT was associated with greater reductions in CG symptoms and functional improvements. Additionally impressive was that the response rate in the CGT condition was twice the rate in IPT [26]. Secondary analyses also supported that CGT led to a significantly greater reduction in illness severity, while bereaved individuals in IPT were still moderately ill at the end of treatment. This study further supported CGT as an effective treatment for CG relative to non-targeted treatments. Furthermore, this study highlighted that although CG and depression are commonly comorbid and share overlapping features, CG is a distinct disorder that requires implementation of specialized treatment.

More recently, a placebo-controlled RCT tested the efficacy of CGT with and without antidepressant pharmacotherapy. Shear et al. [25] examined whether CGT could be enhanced with the addition of the antidepressant, citalopram (CIT; [25]). A multisite RCT included 395 bereaved individuals who met criteria for CG. Individuals were recruited nationally and treated at medical centers in four, large urban areas [25]. Bereaved individuals across the four sites were randomized into four conditions: CIT, placebo (PLA), CGT + CIT, or CGT + PLA, and were stratified by presence of major depressive disorder. CGT was delivered in 16 sessions over a 16–20-week treatment period. Across all four conditions, individuals received pharmacotherapy with flexible dosing, psychoeducation, grief monitoring, and encouragement to engage in activities [25]. When comparing CGT + CIT to CGT + PLA, the addition of an antidepressant, CIT, did not significantly improve treatment outcomes. However, results indicated that

enhancing CGT with CIT (CGT + CIT vs. CGT + PLA) did optimize the treatment of depressive symptoms associated with CG [25]. When comparing within the CIT medication conditions, (CIT alone vs. CIT + CGT), results indicated that enhancing medication treatment with CGT did improve treatment outcomes [25]. The authors concluded that although addition of antidepressant medication to CGT did not appear to enhance reductions in CG symptoms, for individuals with comorbid depression, supplementing CGT with antidepressant medication was effective in targeting associated depressive symptoms [25]. Furthermore, these findings suggest that a combination of CGT with citalopram is more effective than medication alone. In sum, CGT is an efficacious treatment for CG and superior to supportive psychotherapies, non-grief-specific treatments (i.e., IPT), and pharmacotherapy alone.

Summary

Bereavement is one of the most stressful experiences individuals face in a lifetime. Approximately 7% of bereaved individuals and 2–3% of the overall population will develop CG [27]. CG is hypothesized to develop because of maladaptive cognitions about the death, avoidance behavior, insufficient integration of the death into one's autobiographical memory, poor coping responses, and disruption of biobehavioral systems that regulate attachment. Although impairing, CG is a treatable condition. Two evidence-based psychotherapy treatments—cognitive behavior therapy and complicated grief treatment—are effective for the treatment of CG. The treatments have many similarities with respect to the nature of interventions delivered. For example, psychoeducation is a core component of both treatments and revisiting and exposure share many similarities. However, the treatments differ somewhat with respect to their emphasis on other strategies (e.g., cognitive restructuring, understanding the nature of the relationship to the deceased), which is due to the theories that inform their interventions. Further

research should identify mechanisms of action in CBT and CGT to increase efficiency of treatments targeting CG symptoms. Additionally, dissemination of knowledge about grief and evidence-based treatments for CG should be prioritized to increase access to care and enhance treatability of this condition.

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Chapter 13

Pharmacotherapy of Pathological Grief Responses

Mary C. Vance and Eric Bui

Introduction

Responses to bereavement, or the death of a loved one, are highly individualized and range on a spectrum from normal and adaptive to pathological and maladaptive. The pathological grief response known as “Complicated Grief” (CG), “Traumatic Grief,” or “Prolonged Grief Disorder” in the literature has been increasingly recognized as a distinct clinical entity in recent decades, resulting in its inclusion in the

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Diagnostic and Statistical Manual, Fifth Edition (DSM-5), as a new diagnosis of Persistent Complex Bereavement Disorder (PCBD) under “Conditions for Further Study → Other Specified Trauma- and Stressor-Related Disorders” [1]. Although the different terms denote slightly different diagnostic criteria sets, we will, in this chapter as in other chapters, assume that these names basically refer to a single phenomenon in prior research, and will use the term Complicated Grief (CG) for consistency.

This increased interest in CG has also been accompanied by a burgeoning of research on its treatments. To date, evidence points to the efficacy of manualized psychotherapies for treating CG, such as Complicated Grief Treatment [2–4]. However, such therapies are resource-intensive, and their dissemination is limited. These drawbacks indicate a need to study other approaches in the treatment of CG, including pharmacological interventions. Thus far, the data on pharmacotherapy for CG is limited and mixed, but continues to expand. In this chapter, we will review the existing literature on the pharmacotherapy of CG. Further, because CG is not the only clinical diagnosis that can develop as a result of the loss of a loved one, we will also briefly summarize current pharmacological guidelines for the treatment of other bereavement-related conditions, including posttraumatic stress disorder and major depressive disorder.

Data from functional magnetic resonance imaging (fMRI) studies suggest that CG may have a specific underlying neurobiology (see Chap. 3 for review). This in turn suggests that CG may be responsive to pharmacotherapy in a way similar to MDD and PTSD. For example, in what can be considered an animal model of pathological grief, it was found that macaques exposed to deprivation from their social group members exhibited significantly lower levels of serotonin and serotonin metabolites in their prefrontal cortices as compared to control macaques [5]. This suggests that the loss of a closely attached group member results in neurotransmitter changes in a brain area critical to executive functioning, and suggests that grief, like depression and PTSD, can result in lower levels of brain serotonergic activity.

Pharmacotherapy of Bereavement-Related Depression and Complicated Grief

While different diagnostic criteria set have been proposed for CG [6, 7], its introduction as a “condition for further study” in the DSM-5 only occurred recently [1]. Clinical trials examining the efficacy of pharmacologic agents for CG are thus scarce, owing in part to its recent recognition as a distinct diagnostic entity. Before criteria for CG were formalized, bereavement-related depression was the diagnosis commonly used to describe pathological grief reactions. The following section will thus include studies examining the efficacy of pharmacotherapy on both CG, and grief symptoms in bereavement-related depression. Table 13.1 summarizes the designs and results of extant studies.

Tricyclic Antidepressant Trials

Early research on the pharmacotherapy of pathological grief responses centered on TCAs, since this class of medication was first-line for depressive symptoms until the advent of SSRIs and other newer-generation pharmacologic agents. Jacobs et al. [8] conducted the first TCA study on bereavement-related depression, in an open-label trial of ten widows and widowers (age range 26–65 years, 80% women). When participants were rated on a global symptom improvement scale after 4 weeks of treatment with desipramine (dose range 75–150 mg/day), four participants were rated as “very much improved” and three as “much improved.” One participant dropped out due to side effects. All of the improved participants also showed significantly reduced depressive symptoms, but only three of the seven reported a significant reduction in grief intensity.

The effect of nortriptyline on bereavement-related depressive symptoms, sleep quality, and grief intensity was examined by Pasternak et al. [9] in another open-label trial of 13 bereaved spouses (mean age 71.1 years, 61.5% women). In their analysis of study completers, it was found that depressive

TABLE 13.1 Summary of results of medication trials in bereavement-related depression and complicated grief

Authors (year)	Design	Population	Duration	Time since loss	Drug	Results
<i>Bereavement-related depression</i>						
Jacobs et al. [8]	Open-label (ITT)	$n = 10$, age range = 26–65, 80% women	4 weeks		Desipramine, 75–150 mg/day	Depressive symptoms: 70% responders Grief symptoms: 37.5% responders
Pasternak et al. [9]	Open-label (SC)	$n = 13$ CG patients, 61.5% women, mean age = 71.1	Median = 6.4 weeks	Mean = 11.9 months	Nortriptyline, mean dose = 49.2 mg/day	Depressive symptoms improvement rate: 68% Grief symptoms improvement rate: 9%

Zisook et al. [10]	Open-label (ITT)	<i>n</i> = 22 for ITT sample, 77.3% women, mean(SD) age = 63.5 (11.0)	8 weeks	4–6 weeks	Bupropion, flexible 150–200 mg/day	ITT: Depressive symptoms improvement rate: 54%
						ITT: Grief symptoms improvement rate: ICG = 18%, TRIG = 5%
	Open-label (SC)	<i>n</i> = 14 for SC sample				SC: Depressive symptoms improvement rate: 73%
						SC: Grief symptoms improvement rate: ICG = 22%, TRIG = 9%

(continued)

TABLE 13.1 (continued)

Authors (year)	Design	Population	Duration	Time since loss	Drug	Results
Reynolds et al. [11]	RCT	$n = 25$ nortriptyline vs. $n = 22$ placebo (vs. $n = 17$ IPT vs. $n = 16$ nortriptyline + IPT), major depressive disorder, TRIG ≥ 45 , 72.5% women, mean age = 66.1	16 weeks	Mean = 8.1 months	Nortriptyline, mean dose = 66 mg/day	Depressive symptoms: nortriptyline group = 56% remission vs. placebo group = 45% remission vs. Nortriptyline + IPT group = 69% remission Grief symptoms: no differential effect of treatments

<i>Complicated grief</i>	
Zygmunt et al. [12]	<p>Open-label (SC)</p> <p>$n = 15$ mean age = 57, 16-week ICG ≥ 20, 73.3% women</p> <p>median = 17 months</p> <p>Paroxetine, flexible 20–50 mg/day</p> <p>Depressive symptoms improvement rate: 51%</p> <p>Grief symptoms improvement rate: ICG = 48%</p>
Shear et al. [13]	<p>Open-label (modified ITT)</p> <p>$n = 17$, ICG ≥ 30</p> <p>16 weeks</p> <p>mean = 3.9 years</p> <p>Escitalopram, flexible 10–20 mg/day</p> <p>ITT: Grief symptoms improvement rate: ICG = 24%</p> <p>Open-label (SC)</p> <p>$n = 7$, ICG ≥ 30</p> <p>SC: Grief symptoms improvement rate: ICG = 35%</p>

(continued)

TABLE 13.1 (continued)

Authors (year)	Design	Population	Duration	Time since loss	Drug	Results
Simon et al. [14]	Case series	$n = 4$, ICG ≥ 25 , 100% women, mean(SD) age = 41.75 (14.4)	10 weeks	>6 months	Escitalopram, flexible 10–20 mg/day	Complicated grief: 100% responders Grief symptoms improvement rate: ICG = 76%
Hensley et al. [15]	Open-label (SC)	$n = 14$ with major depressive disorder and CG	12 weeks	>6 months	Escitalopram, flexible 10–20 mg/day	Grief symptoms improvement rate: ICG = 21%

Notes: *RCT* randomized controlled trial, *SC* study completers, *ITT* intention to treat, *TRIG* Texas revised inventory of grief, *ICG* inventory of complicated grief

symptoms were significantly reduced after a median treatment period of 6.4 weeks at a nortriptyline mean dose of 49.2 mg/day. Grief intensity also improved, but only marginally so (9.3% decrease in grief intensity).

Reynolds et al. [11] performed the only randomized controlled trial on a tricyclic antidepressant for bereavement-related depression. Eighty older adults (mean age 66.1 years, 72.5% women) were randomized into one of four arms: nortriptyline alone ($n = 25$), placebo alone ($n = 22$), nortriptyline plus interpersonal therapy (IPT) ($n = 16$), or placebo plus interpersonal therapy ($n = 17$). Participants were required to meet criteria for MDD and to have high grief intensity on a grief symptom scale following the death of a spouse. Following 18 weeks of treatment at a mean nortriptyline dose of 66 mg/day, 69% of participants in the nortriptyline plus IPT group achieved remission of depression. In comparison, 56% achieved remission with nortriptyline alone, 45% with placebo alone, and 29% with placebo plus IPT. Controlling for age, nortriptyline was found to have a significant effect over placebo for bereavement-related depression, but no effect was found for IPT or for nortriptyline plus IPT. Additionally, no differential effect was found for any treatment condition on grief intensity.

In sum, trials assessing the efficacy of TCAs for pathological grief responses are few. In the three that have been conducted, TCAs were uniformly found to be effective in the treatment of bereavement-related depressive symptoms, as expected based on prior literature and clinical results. However, all three trials also found that TCA pharmacotherapy was either marginally efficacious or not efficacious in reducing pathological grief symptoms. Of interest, this evidence supports the hypothesis that pathological grief reactions are a distinct clinical entity with a different treatment response profile than depression. Thus, as suggested by these trials, it may be difficult to evaluate the efficacy of pharmacological agents for CG in the context of comorbid depression.

Selective Serotonin Reuptake Inhibitor Trials

The advent of SSRIs coincided with the operationalization of CG. Zygmunt et al. [12], in an open-label trial, examined the use of paroxetine in the treatment of 15 individuals with CG after the loss of a loved one (mean age 57 years, 73.3% women). These participants were concurrently enrolled in a study for psychotherapy treatment development. After 16 weeks of treatment with paroxetine at a median dose of 30 mg/day, grief symptoms decreased by 53%, while depression symptoms decreased by 54%. When compared to a separate, ongoing trial of nortriptyline for bereavement-related depression, it was found that results were similar: both agents yielded reductions in depressive and grief symptoms; and in both cases, there was a greater improvement in depressive symptoms than in grief symptoms. Moreover, since the paroxetine group was more heterogeneous than the nortriptyline group, with great chronicity and comorbidity of illness, the authors suggested favoring paroxetine in clinical practice.

Shear et al. [13] completed another open-label trial of escitalopram on 17 participants diagnosed with CG. The study duration was 16 weeks, with an escitalopram starting dose of 10 mg/day and an option to increase the dose to 20 mg/day in the fourth week. At the end of 16 weeks, grief symptoms had improved by 35% in the study completers and only 24% in the intention-to-treat sample (defined as having attended at least one session).

Simon et al. [14] prospectively examined four patients with CG in a case series on the use of open-label escitalopram on the treatment of complicated grief (mean age 41.8 years, 100% women). The study was conducted for 10 weeks at a flexible dosing range of escitalopram from 10 to 20 mg/day. At study completion, 100% of participants responded with a rating of “very much improved” on a global symptom improvement scale. Both grief scores and depression scores were also significantly improved.

Hensley et al. [15] conducted another open-label trial of escitalopram on 30 individuals with bereavement-related

depression. Of these participants, 14 met diagnostic criteria for CG in addition to MDD, while 15 only met criteria for MDD. After a 12-week trial of flexibly dosed escitalopram (dose range 10–20 mg/day), 66% of subjects experienced a 50% or greater reduction in depressive symptoms. When analyzed by CG diagnosis, grief scores were reduced by 21% in the CG group and by 39% in the uncomplicated grief group; this difference was not statistically significant. As measured by a treatment response of “very much improved” or “much improved” on a global symptom improvement scale, 83% of the whole sample experienced improved depressive symptoms, while 45% experienced improved grief symptoms.

The first randomized controlled trial of an SSRI for CG was recently conducted [4]. In this study, the effect of citalopram on CG symptoms was assessed with and without concurrent psychotherapy (CGT). The total sample consisted of 395 adults across four sites in the USA (mean age 53, 78% women). Subjects were divided into four groups: citalopram alone ($n = 101$), placebo alone ($n = 99$), citalopram with CGT ($n = 99$), and placebo with CGT ($n = 96$). Over 20 weeks of treatment, citalopram was flexibly dosed to its maximum allowable daily dose, which decreased during the course of the study from 60 to 40 mg/day due to an alteration of US Food and Drug Administration guidelines for this medication. The resultant median dose of citalopram was 40 mg/day. Global symptom improvement assessments anchored in CG were administered every 4 weeks, with treatment response defined as a rating of “much improved” or “very much improved.” At the end of the treatment period, CGT was found to lead to a significant improvement in grief symptoms, but the addition of citalopram did not affect CGT outcome. Depression symptoms were noted to decrease significantly when citalopram was added to CGT, and conversely adding CGT to citalopram also significantly improved citalopram outcome. However, there was no significant difference between citalopram and placebo at either week 12 or week 20 on grief symptom severity.

Taken together, these trials yield mixed evidence on the efficacy of SSRI antidepressants for the treatment of CG. Earlier trials were more promising, with SSRIs demonstrating high rates of response for grief symptoms that were at least comparable to those of TCAs. In comparison to reduction in depressive symptoms, however, reduction in grief symptoms was less marked, paralleling the findings with TCAs. Moreover, a randomized controlled trial found no difference between SSRI and placebo in grief symptom reduction, and no improvement in therapy outcome for CG when an SSRI was added. However, the trial strongly suggested that medication and therapy had a synergistic effect on improving depressive symptoms when one was added to the other.

Other Medication Trials

TCA and SSRI trials comprise the bulk of pharmacotherapy research in CG, but there is also a study on bupropion and a study of diazepam in the management of grief symptoms. Zisook et al. [10] examined the effect of bupropion sustained release (SR) for bereavement-related depression in an open-label study of 22 participants who had lost their spouses (mean age 63.5 years, 77.3% women). Participants were treated for 8 weeks with bupropion SR at a flexible dose ranging from 150 to 300 mg/day. Fourteen participants completed the study, yielding a dropout rate of 36%. Depression and CG symptoms were both found to be improved; however, as with other studies, the improvement in depression was of greater magnitude than the improvement in CG. After 8 weeks of treatment, an intention-to-treat analysis showed a 5–18% reduction in grief, as compared to a 54% reduction in depression. Therefore, the results of this bupropion trial accord with those of TCA and SSRI trials, showing reduction in depressive symptoms greater than reduction in grief symptoms when an antidepressant medication is administered for the treatment of grief.

Warner et al. [16] conducted the only known randomized controlled trial of a benzodiazepine on early grief symptoms. Thirty participants were randomized to receive either 20 tablets of 2 mg of diazepam or placebo within 2 weeks of the loss of a spouse or partner. The diazepam was prescribed as a PRN medication for use up to three times daily for the 6-week study duration, and no further prescriptions were provided. At 6-month follow-up, no statistically significant difference was found between the diazepam group and the placebo group in grief symptoms. Of note, participants who received placebo reported fewer sleep problems (greater ability to get to sleep quickly, fewer bad dreams) than those who received diazepam.

These results showing neutral or negative clinical effects of benzodiazepines on psychiatric symptoms are consistent with prior research. Multiple studies on the use of benzodiazepines in PTSD [17–19] have shown either no benefit or harm with benzodiazepines after trauma. Taken together, these data suggest caution in prescribing benzodiazepines for CG, in a context of frequent prescription in the aftermath of bereavement [20].

Trials of Combined Pharmacotherapy and Psychotherapy

The combined efficacy of pharmacotherapy and psychotherapy has been assessed in several studies. Reynolds et al.'s open-label study [11], as above, showed no significant effect for combined nortriptyline and IPT in the treatment of bereavement-related depression. In a randomized controlled trial, Shear et al. [2] examined the effect of CGT vs. IPT for loss in the treatment of CG while allowing for a concurrent, stable dose of antidepressant or benzodiazepine medication. It was found that, in both the CGT and the IPT arms, antidepressant use concurrent with therapy was marginally associated with a better outcome. A follow-up analysis of this naturalistic data showed that participants who were on a

concomitant antidepressant were significantly more likely to complete the full course of CGT than those who were not (91% vs. 58% completion); however, no such effect was found for IPT [21]. Conversely, stable dosing of a benzodiazepine while receiving therapy was significantly associated with an improved outcome in the IPT group but not in the CGT group. Moreover, even after controlling for age, gender, race, and psychiatric comorbidity, participants from the full sample on concurrent antidepressant therapy were more than twice as likely to be treatment responders as participants not on antidepressants. Finally, as mentioned above, Shear et al.'s randomized controlled trial [4] on citalopram and psychotherapy (CGT) showed that, while the combination of CGT and citalopram did not improve CG outcomes, depressive symptoms were significantly decreased when citalopram was added to therapy.

Explanations for some of these results can be posited based on patient experience. In the Zisook et al. [10] study previously described, some patients reported that the treatment of their MDD symptoms enabled them to begin grieving, to grieve more intensely, or to confront situations that they had previously avoided. This suggests that patients whose depression is treated pharmacologically may be more prepared to engage in therapy work on grief than patients who remain depressed. An increase in grief intensity after the treatment of depression, which may have the effect of reducing psychological numbing or avoidance, might also account for the attenuated improvement of grief symptoms as compared with depressive symptoms seen in multiple studies.

Suggested Guidelines

Given the mixed and scarce data on pharmacotherapeutic agents in the treatment of CG, limited evidence-based guidelines can be given about strategies for intervening with pharmacotherapy in grief. In the acute post-loss phase, when symptoms may be at their most severe, recently bereaved

individuals may experience heightened anxiety and even meet diagnostic criteria for acute stress disorder (ASD). Under these circumstances, clinicians frequently prescribe benzodiazepines for their anxiolytic properties. However, as previously described, the evidence base points away from the use of benzodiazepines in the peritraumatic and posttraumatic periods, including following a traumatic loss. Other anxiolytic medications with less addictive potential and less risk of harm post-trauma, including buspirone or hydroxyzine, might be considered instead.

In the longer-term treatment of pathological grief responses, an important first step is to clarify the diagnosis. In addition to meeting the bereavement-specific diagnosis of CG, other psychiatric conditions, including PTSD, MDD, or even an anxiety disorder, might develop or worsen as a result of losing a loved one. Given the evidence base supporting pharmacotherapy for anxiety disorders, PTSD, and MDD, it would be good practice to follow the standard clinical guidelines for those conditions when bereaved patients meet their diagnostic criteria for and pharmacologic treatment is indicated. This treatment approach should be highlighted especially for bereavement-related MDD, since the bereavement exclusion, which systematically excluded bereaved individuals from being diagnosed with depression unless specific additional criteria were met, was removed in 2013 with the fifth iteration of the DSM.

Briefly, first-line pharmacological treatment for MDD (following bereavement or not) includes SSRIs and SNRIs. FDA-approved SSRIs for the treatment of MDD are fluoxetine, citalopram, escitalopram, paroxetine, and sertraline; FDA-approved SNRIs for the treatment of depression include venlafaxine and duloxetine. Similarly, bereaved individuals who meet criteria for PTSD may be offered sertraline and paroxetine, the first-line, FDA-approved SSRIs for PTSD. Non-FDA-approved antidepressant medications found efficacious for PTSD include the SSRI fluoxetine, and the SNRI venlafaxine [22]. There is no evidence, to date, to suggest that bereavement-related PTSD or MDD would

respond differently to these agents than their non-bereavement-related counterparts. For example, paroxetine initiated at 20 mg/day, up to a maximum dose of 50 mg/day, and sertraline initiated at 25 mg/day at a dose range of 50–200 mg/day can be recommended based on the available evidence base.

If a patient meets criteria for CG but not for PTSD, or MDD, then specific treatment for CG should be explored. Data on the efficacy of psychotherapeutic interventions, including CGT, are more robust than for pharmacotherapeutic interventions, and therefore therapy should be considered the first-line treatment recommendation for pathological grief responses, with medications as adjunctive treatment. The evidence base for TCAs in CG is stronger than that for SSRIs, but TCAs have reduced tolerability and a worse safety profile compared to SSRIs, which makes it difficult to recommend them as first-line agents. TCAs may thus be considered second-line agents. Desipramine at a dose range of 75–150 mg/day and nortriptyline at a mean dose of 66 mg/day (targeting plasma levels of 80–120 ng/mL) have been evaluated in trials. The efficacy of other antidepressant medications on grief reactions has not been tested, aside from one trial on bupropion. Based on that study, bupropion SR at a dose range of 150–300 mg/day can also be recommended as an adjunctive medication especially in the presence of comorbid depression, albeit with a weaker evidence base.

Future Directions

Grief pharmacotherapy research has been scarce thus far, with only one randomized controlled trial available on the TCA class of medications and one on the SSRI class. This dearth of an evidence base stems at least in part from the lack of diagnostic consensus on pathological grief reactions and, until recently, the lack of inclusion of a CG diagnosis in the DSM. Because CG is now formally operationalized in the DSM as PCBD under “Conditions for Further Study,” an

increase in research interest around this diagnosis is expected. Studies assessing the mechanisms by which pharmacotherapy impacts grief symptoms would shed light on the results of drug trials seen thus far. Additional randomized controlled trials, especially on different medication classes that have not yet been tested for efficacy in CG, would have the potential to increase the array of evidence-based pharmacotherapy options for patients experiencing distress after a loss.

One interesting psychopharmacologic avenue to consider is the targeting of reward pathways in the brain. Prior studies have shown that CG may share some biological characteristics of addictive illnesses. In an fMRI study, both individuals with CG and individuals with noncomplicated grief exhibited pain-related neural activity when presented with reminders of the deceased; however, only CG subjects showed reward-related neural activity in the nucleus accumbens [23]. Reward-related nucleus accumbens activation has previously been associated with “craving” phenomena in substance use disorders, and social attachment has been framed as triggering reward pathways similar to those in addiction [24]. This theoretical framework and neuroimaging evidence supports the hypothesis that CG has elements of a craving or withdrawal response to severed attachment. As “medication-assisted treatment” has been shown to be effective in substance use disorders, so might a similar approach with medications benefit CG.

The efficacy of medications that have already shown efficacy in reducing craving in substance use disorders, such as naltrexone (for review, see [25]), on CG need further investigation. In addition, since reward-related nucleus accumbens activity is closely linked with increased dopaminergic transmission, dopamine antagonists in the antipsychotic class of medications have been explored for use in cravings. To date, there is mixed data about the efficacy of antipsychotics in addiction [26, 27]. Issues with the tolerability and safety profiles of antipsychotics would likely limit their clinical use in CG, but drugs with a dopaminergic mechanism of action may nevertheless yield potentially fruitful directions for future research.

A human study also revealed that, as compared with their counterparts who were experiencing an uncomplicated grief reaction, individuals with CG exhibited a significantly flatter slope in cortisol levels across the day [28]. A more recent study measuring catecholamine levels pre- and post-psychotherapeutic treatment additionally demonstrated that participants with high epinephrine levels pre-treatment had significantly higher post-treatment grief intensity as assessed by the ICG [29]. This suggests that CG's neurobiology might involve dysfunction in the stress system and HPA-axis, and targeting this pathway pharmacologically may hold promise in alleviating CG symptoms.

Finally, recent research has consistently reported that loss-related emotional pain is a hallmark feature of the grief reaction. Emotional pain refers to pain affect (*i.e.*, the felt unpleasantness of pain) in response to loss of social connection or value [30], such as the death of a loved one. Early conceptualizations of grief emphasized a central role to emotional pain [31], and a recent network analysis study supported it as the most central symptom of CG [32]. Recent investigations reporting that analgesic medication might be efficacious in reducing social pain, another form of psychological pain (e.g., [33]), suggest that targeting pain might be another avenue for investigation.

Conclusions

Clinical and neurobiological evidence points to CG, currently operationalized as PCBD in the DSM-5, as a distinct diagnostic entity that has some overlap with MDD and PTSD. While psychotherapy remains the first-line treatment overall, the limited research available to date supports the use SSRIs as first-line pharmacotherapy for CG. The use of antidepressant medications with concurrent therapy may also increase the efficacy of psychotherapeutic interventions. Further studies are needed to better elucidate the neurobiology of CG and to find effective pharmacological treatments.

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Chapter 14

Grief Reactions in Diagnostic Classifications of Mental Disorders

**Claudia Carmassi, Carlo A. Bertelloni,
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Introduction

Bereavement is a universal experience and grief is the natural reaction to bereavement. Although bereavement is a ubiquitous life event, it is often followed by emotional suffering and adjustment challenges. This instinctive and physiological reaction, called acute grief, is one of the most distressing experiences in a lifetime. It encompasses a lot of grieving emotions that evolve over time, like sadness, sorrow, guilt, regret, yearning, fear, anger, anguish, and loneliness, as well as confusion about one individual’s identity and social role, and a sense of disbelief or shock that a loved one is gone. Despite the transcultural nature of grief, its manifestations and temporal evolution are unique to each loss, depending on the characteristics of the relationship with the deceased. It is

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normal for these feelings to fluctuate in their expression and intensity over time, or to be absent at times. But grief is not only about pain. For most people, painful experiences and memories are intermingled with positive feelings, such as relief, peace, and happiness, which foster resilience.

Authors have conceptualized grief as a somewhat adaptive process, that helps maintain relationships (both with the deceased and others), and experiencing acute grief when losing a loved one can be considered an adaptive response. Thus, because it is triggered by a universal human experience, and because it is generally transient and time-limited in nature, acute grief seldom comes to the notice of the healthcare professionals and is therefore often considered as a normal condition rather than a mental disorder [1–3].

Freud was the first to introduce the concept of grief in the psychological lexicon. Prior to his publication on mourning and melancholia in 1917, few researchers had explored the physiology and manifestations of normal versus pathological grief process. Later on across the twentieth century, increasing studies have shown an association between the loss of a loved one and a range of mental health disorders, particularly major depression and Post-Traumatic Stress Disorder (PTSD) [4–10]. Most recently, increasing evidence has emerged on pathological grief processes, distinct from depression or PTSD, that have been differently named as *Complicated Grief* (CG), *Traumatic Grief*, and *Prolonged Grief Disorder* (PGD), and there is now evidence that these conditions—or this condition if we consider they all basically refer to the same condition—are significantly associated with serious psychosocial and health problems, including suicidality, substance abuse, and cardiovascular disease [1, 11–14]. All these studies lead, for the first time, to the acknowledgment of specific pathological grief reactions in the latest revisions of international nosographic classifications with Persistent Complex Bereavement Disorder PCBD being introduced in the latest version of the Diagnostic and Statistical Manual for Mental Disorders (DSM) and proposals also being debated for the updated version of the

International Classification of Diseases (ICD). Contrary to other chapters, this chapter will attempt to describe all the different loss-specific disorders (CG, PGD, PCBD) as distinct entities, allowing comparisons between them, without trying to solve which criteria set is the best.

1. Time frame of Mourning

Mourning is a journey characterized by peaks and troughs, associated with positive and negative feelings that evolve over time until all these emotions and feelings are completely integrated. Following the phase approach to grief proposed by Bowlby, grief has been identified as pathological when not providing a gradual recovery or present excessive duration [12]. Authors have argued that 4–6 months after a loss, most bereaved people usually begin to feel significantly better despite cultural or personal aspects [15–18]. Several studies on bereaved individuals showed that grief symptomatology at 6 months after the loss predicted poor physical and mental health status, risk of cancer, high blood pressure, heart trouble, smoking, eating problems, and suicidality 1–2 years later [9, 16, 19, 20].

In line with these converging pieces of evidence, a specific pathological grief reaction like CG/PGD can be diagnosed at least 6 months after the loss [21, 22]. Shear et al. [23] also suggested a minimum period of 1 month of symptoms for CG diagnosis, considering that their presence for few days during anniversary or stressful period would not be indicative of a disorder. Conversely, DSM-5 was particularly cautious in adopting a 12-month minimum requirement since the death in order to discriminate grief reactions that are predictive of persistent problem [24]. This caution in the diagnostic timeframe of PCBD was, on one hand, protective against the accusations of excessive pathologizing of a normal reaction but, on the other hand, prevented from identifying individuals at high risk for physical and mental long-term complications. As argued by some, the decision to set the “time since” criterion to 12 months “*is not only arbitrary but also contrary to published empirical research findings*” [25].

2. Complicated Grief

CG has been defined as a chronic impairing form of grief resulting from factors interfering with the healing process, that affect about 2–3% of the population worldwide [21, 23, 26]. Prigerson and colleagues coined the term “CG” in the middle of 1990s, referring to “*poor adjustment to bereavement*” [27]. Therefore, the term “complicated” refers to a superimposed process that alters grief and modifies its course for the worse.

CG symptoms have been associated with significant distress, severe interference with functioning, and the lack of ability to find meaning and purpose in life. CG can occur after the loss of any close relationship but its prevalence may reach approximately 10 or 20% after the death of a loved one [28]; its onset is more common after the loss of a child, or following a violent, unexpected death and less frequent in subjects who experience the loss of a parent, grandparent, sibling, or close friend [29]. The prevalence of CG has been reported to be highest among elderly women [30]. In clinical practice, untreated patients with CG present a prolonged and, in some cases, chronic symptomatology. The specificity of CG is the presence of persistent and strong yearning and longing for the deceased sadness, and isolation feelings; often these symptoms are accompanied by intense desire to be with the deceased also expressed with persistent and intrusive thoughts or images, disbelief feelings, or an inability to accept the reality of the death. Questions, worries, and rumination are usually persistent, focused on guilt or self-blame for the circumstances and the consequences of the death, and with positive emotions commonly accompanied by guilt. Individuals with CG are often shocked or stunned by the death and they may become emotionally numb and feeling detached from others: in their belief happiness and joy are inextricably linked to the deceased. They may have negative or even catastrophic thoughts about the future or be constantly worried about the aftermaths of the bereavement, leading friends and relatives to be frustrated as they cannot provide help. This is critical, as friends and family may in

return stop contacting the subject, which then worsen feelings of loneliness and emptiness [1, 2]. Excessive avoidance of reminders of the loss is also common, as is the compulsive proximity seeking by insistently recalling or by viewing, touching, or smelling items associated with the loved one. A person with CG may have a diminished sense of self or discomfort with a changed social role and is often confused by what appears as an endless grief. Suicidal thoughts are very frequent in CG and sometimes are at a level that is of concern. Suicide is attempted in order to join the deceased person or to end a life that has become unbearable without the deceased [6, 7, 23, 31].

The Inventory of Complicated Grief (ICG) is a self-report instrument validated to identify CG that assesses the current presence of core CG symptoms associated with impairment and poor outcomes [32] such as intense yearning and preoccupation with the deceased; anger and bitterness about the death; shock and disbelief; estrangement from others; hallucinations of the deceased; and behaviour change, including avoidance or proximity seeking behaviour [33]. The original version consists of 19 items and respondents rate the frequency with which they experience each item on a 5-point scale (0–4), ranging from “never” to “always” (0 = never; 1 = rarely; 2 = sometimes; 3 = often; 4 = always). The ICG presents good psychometric properties and it has been used to assess the presence of CG by a large number of studies. Originally tested by Prigerson and colleagues in 97 elderly bereaved men and women demonstrated concurrent validity with high correlations with the Beck Depression Inventory total score [34] ($r = 0.67, p < 0.001$), the Texas Revised Inventory of Grief [35] score ($r = 0.87, p < 0.001$), and the Grief Measurement Scale [36] score ($r = 0.70, p < 0.001$). Respondents with ICG scores greater than 25 were in the upper quartile of the sample and reported significantly more impairment in social, general, mental, and physical health functioning and reported higher levels of bodily pain than those with ICG scores less than or equal to 25. Subsequent treatment and clinical studies used a cutoff score of 30 or higher to determinate CG [23], based on the differential

treatment response among individuals identified with this symptom threshold. Factor analysis conducted in a study on 782 bereaved individuals identified six clinical dimensions: yearning and preoccupation with the deceased, anger and bitterness, shock and disbelief, estrangement from others, hallucinations of the deceased, and behaviour change as avoidance and proximity seeking [37]. A modified, shorter version of the original ICG is also available, named Inventory of Complicated Grief-Revised (ICG-R), consisting of 15 questions with a 5-point Likert scale, a functional criterion, and a duration criterion of 6 months [33].

ICG is currently the only validated scale to diagnose CG and has been increasingly used in international trials and studies being translated and validated in other languages [38–41]. A structured clinical interview for complicated grief (SCI-ICG) was also recently developed to assess all symptoms of CG, as well as symptoms pertaining to PGD and PCBD. Psychometric properties of this instrument examined among 281 treatment seeking adults with CG who lost a loved one at least 6 months prior, showed good internal consistency, reliability, and validity [42]. The proposed diagnostic criteria for CG are reported in Table 14.1.

TABLE 14.1 Proposed criteria for complicated grief

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- A. Event: Bereavement (loss of a significant other) from at least 6 months
- B. Separation distress: One (or more) of the following symptoms of persistent intense acute grief has been present for a period longer than is expected by others in the person's social or cultural environment:
1. Persistent intense yearning or longing for the person who died
 2. Frequent intense feelings of loneliness or like life is empty or meaningless without the person who died
 3. Recurrent thoughts that it is unfair, meaningless, or unbearable to have to live when a loved one has died, or a recurrent urge to die in order to find or to join the deceased
 4. Frequent preoccupying thoughts about the person who died, e.g. thoughts or images of the person intrude on usual activities or interfere with functioning
-

TABLE 14.1 (continued)

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- C. Cognitive, emotional, and behavioural symptoms: Two (or more) of the following symptoms are present for at least 1 month:
1. Frequent troubling rumination about circumstances or consequences of the death, e.g. concerns about how or why the person died, or about not being able to manage without their loved one, thoughts of having let the deceased person down, etc.
 2. Recurrent feeling of disbelief or inability to accept the death, like the person can't believe or accept that their loved one is really gone
 3. Persistent feeling of being shocked, stunned, dazed, or emotionally numb since the death
 4. Recurrent feelings of anger or bitterness related to the death
 5. Persistent difficulty trusting or caring about other people or feeling intensely envious of others who haven't experienced a similar loss
 6. Frequently experiencing pain or other symptoms that the deceased person had, or hearing the voice or seeing the deceased person
 7. Experiencing intense emotional or physiological reactivity to memories of the person who died or to reminders of the loss
 8. Change in behaviour due to excessive avoidance or the opposite, excessive proximity seeking, e.g. refraining from going places, doing things, or having contact with things that are reminders of the loss, or feeling drawn to reminders of the person, such as wanting to see, touch, hear, or smell things to feel close to the person who died (Note: Sometimes people experience both of these seemingly contradictory symptoms.)
- D. Timing: The duration of symptoms and impairment is at least 1 month
- E. Impairment: The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning, where impairment is not better explained as a culturally appropriate response
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Prolonged Grief Disorder

PGD is intended to describe severe and disabling grief reactions that do not remit in the 12 months after the death of a significant other. The core of the diagnosis includes persistent yearning or missing the deceased, and preoccupation with the circumstance of the death. In addition to this central element, there are additional symptoms that could be present such as difficulty accepting the death, feelings of loss of a part of oneself, anger about the loss, guilt or blame regarding the death, or difficulty in engaging with new social or other activities due to the loss. Importantly, these persistent reactions need to be outside one's cultural norm, recognizing the variability in societal frameworks of mourning and grief. Proponents of PGD support the difference of symptoms of persistent grief from those observed in the normative reactions to bereavement in the acute phase, they believe not all grief is normal, in particular, prolonged, unresolved, intense grief is not normal. From the PGD perspective, grief symptoms themselves are neither atypical nor pathological and PGD is characterized by normal symptoms of grief that remain too intense for too long. That is, all symptoms of grief are normal, but some combination of their severity and their duration is not. For PGD, the pathology is in the time course of the symptoms, not in the symptoms per se [25].

PGD has been proposed as a new diagnosis for the International Classification of Diseases-11 (ICD-11) new group "Disorders specifically associated with stress", describing abnormally persistent and disabling responses to bereavement. This new ICD-11 section includes adjustment disorder, PTSD, and complex PTSD, identifying a proposed group of disorders specifically related to stress. Specifically, this set of conditions have distinct psychopathology and require prior exposure to an external stressful event, or adverse experiences of exceptional character or degree; events may range from less severe psychosocial

stress (*life events*) to the loss of a close other, single traumatic events, and repeated or prolonged traumatic stress of exceptional severity. The introduction of PGD is a response to the increasing evidence of a distinct and debilitating condition that is not adequately described by current ICD diagnoses. It is defined as a severe and enduring symptom pattern of yearning or longing for the deceased or a persistent preoccupation with the deceased. This reaction may be associated with difficulties accepting the death, feelings of loss of a part of oneself, anger about the loss, guilt or blame regarding the death, or difficulties in engaging with new social or other activities due to the loss. Importantly, prolonged grief disorder can only be diagnosed if symptoms are still apparent after a period of grieving that is normative within the cultural context (e.g. 6 months or more after the death), the persistent grief response goes far beyond expected social or cultural norms, and the symptoms markedly interfere with one's capacity to function. If normative grieving in the individual's culture goes beyond 6 months, the duration requirement should be extended accordingly. Although most individuals report at least partial relief from the acute pain of grief by around 6 months following bereavement, those who continue experiencing severe grief reactions beyond this time frame are likely to have a significant impairment in their general functioning [21]. Many studies from around the world, including both Western and Eastern cultures, have identified a small but significant portion of bereaved people who meet this definition.

It is important to note that diagnostic criteria have evolved over time, such that some studies might be referring to PGD using CG criteria and vice versa, adding to some confusion in the field. Factor analyses repeatedly demonstrated that the central component of PGD (yearning for the deceased) is distinct from nonspecific symptoms of anxiety and depression. Distinctive neural dysfunctions and cognitive patterns associated with PGD

have been described [23, 43] and patients can experience serious psychosocial and health problems, including other mental health difficulties such as suicidality and substance abuse, harmful health behaviours, or physical disorders such as high blood pressure and elevated rates of cardiovascular disorder [44].

Regarding pharmacological treatment, PGD does not respond to antidepressant medication though bereavement-related depressive syndromes do [45]. Psychotherapy approaches that strategically targets the symptoms of PGD has been shown to alleviate their occurrence more effectively than treatments that target depression [18]. The introduction of PGD as a diagnosis has caused debate because of concerns that it could pathologize normal grief responses [46]. The Working Group considered this issue thoroughly and emphasized several points: the diagnostic requirements being carefully drawn to respect the variation of “normal” processes and to pay attention to cultural and contextual factors; the diagnosis only applying to that minority (<10%) of bereaved people who experience persistent impairment; the recognition of marked cultural variations in grief manifestations to be taken into account for diagnostic decisions; the consideration that many people will experience fluctuating distressing grief responses beyond 6 months from the death of close persons not being necessarily candidates for a PGD diagnosis due to a lack of persistence and debilitation.

Epidemiological findings have corroborated PGD as a public health issue and that accurate identification of people with the disorder could reduce the likelihood of inappropriate treatment. Proposed diagnostic criteria for PGD are reported in Table 14.2.

TABLE 14.2 Proposed criteria for prolonged grief

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- A. Event: Bereavement (loss of a significant other)
- B. Separation distress: The bereaved person experiences yearning (e.g. craving, pining, or longing for the deceased; physical or emotional suffering as a result of the desired, but unfulfilled, reunion with the deceased) daily or to a disabling degree
- C. Cognitive, emotional, and behavioural symptoms: The bereaved person must have five (or more) of the following symptoms experienced daily or to a disabling degree:
1. Confusion about one's role in life or diminished sense of self (i.e. feeling that a part of oneself has died)
 2. Difficulty accepting the loss
 3. Avoidance of reminders of the reality of the loss
 4. Inability to trust others since the loss
 5. Bitterness or anger related to the loss
 6. Difficulty moving on with life (e.g. making new friends, pursuing interests)
 7. Numbness (absence of emotion) since the loss
 8. Feeling that life is unfulfilling, empty, or meaningless since the loss
 9. Feeling stunned, dazed, or shocked by the loss
- D. Timing: Diagnosis should not be made until at least 6 months have elapsed since the death
- E. Impairment: The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning (e.g. domestic responsibilities)
- F. Relation to other mental disorders: The disturbance is not better accounted for by major depressive disorder, generalized anxiety disorder, or post-traumatic stress disorder
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Persistent Complex Bereavement Disorder and Loss-Related Disorders in the DSM

The latest edition of the Diagnostic and Statistical Manual (DSM-5, [24]) introduced for the first time extremely important changes for what concern pathological grief reactions, not only suggesting diagnostic criteria for a possible disorder related to a pathological grief reaction, but also better delineating the boundaries with other mental disorders potentially related to loss.

Grief has been addressed in different chapters of the DSM-5. First a new pathological entity named PCBD was introduced in the section III chapter *Conditions for Further Study*. Important changes were also addressed to diagnostic criteria for Major Depressive Disorder (MDD) when related to a loss, with the elimination of the so-called *bereavement exclusion*. Finally, within the chapter of “Trauma and Stressor related disorder” are included disorders also potentially related to significant losses, such as PTSD, Acute Stress Disorder (ASD), and Adjustment Disorder (AD).

(a) Persistent Complex Bereavement Disorder

With the inclusion of PCBD, the DSM-5 recognizes the possible development of persistent and debilitating symptoms of grief in a minority of subjects facing the loss of a significant other. The construct of PCBD originates from the strong evidence that there is a set of grief symptoms that forms a unitary dimension, distinct from symptoms of depression, PTSD, and other anxiety disorders, that is associated with severe distress and disability, even when controlling for co-occurring symptoms of depressive and anxiety disorders [21, 23, 44]. Although empirically based criteria sets for both PGD and CG had already been proposed, the DSM-5 Workgroup chose a new name, PCBD, and set of diagnostic criteria by reviewing the literature and obtaining expert consultation and consensus discussions that incorporated aspects of both PGD and CG.

PCBD is diagnosed only if at least 12 months (6 months in children) have elapsed since the death of someone with whom the bereaved had a close relationship (Criterion A). This time frame discriminates normal grief from persistent grief. The condition typically involves a persistent yearning/longing for the deceased (Criterion B1), which may be associated with intense sorrow and frequent crying (Criterion B2) or preoccupation with the deceased (Criterion B3). The individual may also be preoccupied with the manner in which the person died (Criterion B4). Six additional symptoms are required, including marked difficulty accepting that the individual has died (Criterion C1) (e.g. preparing meals for them), disbelief that the individual is dead (Criterion C2), distressing memories of the deceased (Criterion C3), anger over the loss (Criterion C4), maladaptive appraisals about oneself in relation to the deceased or the death (Criterion C5), and excessive avoidance of reminders of the loss (Criterion C6). Individuals may also report a desire to die because they wish to be with the deceased (Criterion C7); be distrustful of others (Criterion C8); feel isolated (Criterion C9); believe that life has no meaning or purpose without the deceased (Criterion C10); experience a diminished sense of identity in which they feel a part of themselves has died or been lost (Criterion C11); or have difficulty engaging in activities, pursuing relationships, or planning for the future (Criterion C12). PCBD requires clinically significant distress or impairment in psychosocial functioning (Criterion D). The nature and severity of grief must be beyond expected norms for the relevant cultural setting, religious group, or developmental stage (Criterion E). Although there are variations in how grief can manifest, the symptoms of PCBD occur in both genders and in diverse social and cultural groups. Some individuals may also experience hallucinations of the deceased (auditory or visual) in which they temporarily perceive the deceased's presence (e.g. seeing the deceased sitting in his or her favorite chair). They may also experience somatic complaints (e.g. digestive complaints, pain, fatigue), including symptoms that had been experienced by the deceased. PCBD

can occur at any age, beginning after the age of 1 year. Symptoms usually begin within the initial months after the death, although there may be a delay of months, or even years, before the full syndrome appears.

In recognition of their lack of validation, PCBD criteria were included in section 3 of DSM-5 “Conditions for Further Study”. As PCBD is only found in this appendix, and not considered a “real” diagnosis, sufferers may not be recognized at all or only treated for depression without receiving a grief-specific psychotherapy. However, in the DSM-5, interestingly, PCBD was listed as an example of the “*Other Specified Trauma- and Stressor-Related Disorders*” diagnostic category. The alternative “usable” diagnosis, adjustment disorder, which would fit the description of some of patients with prolonged grief, is defined by a duration of not more than 6 months “once the stressor or its consequences have terminated” [24]. Treatment studies reveal that time between the actual loss and start of treatment is several years on average [47, 48], suggesting that adjustment disorder the best fitting diagnosis either. Currently, there is considerable interest in assessing the ability of PCBD criteria to accurately identify bereaved individuals in need of clinical intervention (e.g. [49, 50]).

(b) Major Depressive Disorder and the *Bereavement Exclusion*

Prior to the 1980 publication of the Diagnostic and Statistical Manual-Third Edition (DSM-III), bereavement was not part of psychiatry’s official nomenclature. The bereavement exception only became an issue with the publication of the DSM-III. In this latter in fact, bereavement was a V code for a “Supplementary Classification of Factors Influencing Health Status and Contact with Health Services” [51]. The DSM-III distinguished between uncomplicated, or a normal reaction to loss, and complicated grief: “*A full depressive syndrome frequently is a normal reaction to such a loss, with feelings of depression and such associated symptoms as poor appetite, weight loss, and insomnia [uncomplicated grief]*”. However, morbid preoccupation with worthlessness, prolonged and marked functional impair-

ment, and marked psychomotor retardation are uncommon and suggest that the bereavement is complicated by the development of Major Depressive Disorder (MDD). Unless an individual experienced severe expressions of grief, he or she was considered to exhibit normal grief. The incentive to include bereavement in the DSM-III came from the need to contextualize bereavement in relation to depressive symptoms. The DSM-III committee noted that depressive symptoms, within the context of bereavement, were a normal reaction to the death of a loved one, whereas if these symptoms occurred outside bereavement, they would be abnormal [52]. Another reason for the reluctance to clinically disentangle grief from MDD is that the symptoms of bereavement and MDD overlap considerably. Sleep disturbance, anhedonia, sad mood, guilt and occasionally suicidal ideation may be present in both conditions [3, 53, 54]. The overall theme that helps one distinguish symptoms of grief from symptoms of MDD is that symptoms of grief are loss centered whereas symptoms of MDD typically are both centered on the self and pervasive.

The addition of the *bereavement exclusion* to the DSM-III was based on the pioneering series of studies initiated by Paula Clayton and colleagues at the University of Washington in the 1960s and early 1970s [55–59]. These studies were based mainly on bereaved widows and widowers and demonstrated that symptoms of depression are exceedingly common in individuals experiencing normal grief for the loss of a loved one [60]. In the first month of bereavement, study participants often experienced symptoms of MDD, including depressed mood, crying, anorexia and/or weight loss, difficulty concentrating and/or poor memory, and sleep disturbance. Most somatic symptoms dramatically improved by the end of the first year. However, insomnia (48%), restlessness (45%), periodic low mood (42%), and crying (33%) persisted in over one-third of participants [55]. The 1-year incidence of a full MDD was high (47% in the bereaved versus 8% in the non-bereaved controls), but rates appreciably declined over the first year (35–42% of the bereaved at 1 month versus 16% at 1 year) [15]. This work laid the foundation for the

bereavement exclusion, as it highlighted the importance of not confusing MDD with a normal phenomenon, grief.

A number of studies on widows and widowers revealing an improvement in their symptoms of depression over time [56] served as the impetus for the guidelines in the fourth edition of the DSM (DSM-IV; [61]). The DSM-IV operationalized the duration of these symptoms as persisting for longer than 2 months after the loss, stating: “The diagnosis of MDD is generally not given unless the symptoms are present 2 months after the loss. However, the presence of certain symptoms that are not characteristic of a “normal” grief reaction may be helpful in differentiating bereavement from a major depressive episode. These include: (1) guilt about things other than actions taken or not taken by the survivor at the time of the death; (2) thoughts of death other than the survivor feeling that he or she would be better off dead or should have died with the deceased person; (3) morbid preoccupation with worthlessness; (4) marked psychomotor retardation; (5) prolonged and marked functional impairment; and (6) hallucinatory experiences other than thinking that he or she hears the voices of, or transiently sees the image of, the deceased person.” These symptoms had to exist for at least 2 weeks, although the diagnosis could not be given until at least 2 months following the death of a loved one. Thus, according to the DSM-IV-TR, an individual who meets all symptomatic, duration and impairment criteria for MDD but is recently bereaved may not have MDD; in contrast, a non-bereaved individual with the same clinical constellation of symptoms, who is recently divorced, impoverished, or disabled, or who cannot identify any recent adversity, does have MDD.

The DSM-5 changed the *bereavement exclusion*, removing the 2-month waiting period [62]. The new criteria allow a bereaved individual to be diagnosed with major depression after 2 weeks of experiencing symptoms, one of the most contentious changes in the DSM-5. For many, removing the *bereavement exclusion* became symbolic of the predominant concerns regarding financial incentives and the respective medicalization of “normal” conditions by DSM-5. Part of the

outcry against this decision is the worry that clinicians will now overdiagnose MDD, especially in individuals who are “just” grieving [63].

On one hand, there are four major arguments that prompted the removal of the *bereavement exclusion* in the DSM-5. First, the changes were based on data from two reviews [64, 65] and recent studies finding no major difference between bereavement-related depression and depression caused from other life stressors in terms of risk factors, intensity, characteristics, biology, symptoms, and response to treatment [53, 62, 64, 66, 67]. The second major argument came from three international studies from Lebanon, Denmark, and France [68–70] revealing that individuals who were excluded from the diagnosis of depression due to bereavement actually had more severe symptoms than those with non-bereavement-related depression [53]. Karam et al. [69] reported that the global symptom profile of depressed individuals and their risk for depressive recurrence was similar in bereaved and non-bereaved subjects, and that the duration of illness was actually longer in the bereaved group. Corruble et al. [68] found that subjects who were excluded from the diagnosis of MDD because of current DSM-IV-TR conventions are, if anything, even more severely depressed than MDD controls without bereavement. Results from these studies suggest that bereaved individuals who are excluded from receiving the diagnosis of major depression might develop more severe and/or persisting depression because they are unable to access different treatments for their depression. A third argument for removing the *bereavement exclusion* in the DSM-5 was that this change would be parallel to existing international criteria in the International Classification of Disease (ICD-10). The unification of the criteria for depression related to bereavement in the DSM and the ICD would make the diagnosis more consistent. Finally, the last rationale for removing the *bereavement exclusion* in the DSM-5 was that clinicians should be able to properly distinguish “*adaptive*” grief from more serious reactions of grief including feelings of isolation and the inability to be

consoled. Moreover, clinicians should evaluate patients' experiences and examine phenomenological differences rather than solely using diagnostic checklists [71]. This idea of the phenomenology of grief comes from the notion that there is a distinction between normal sorrow and severe depression that clinicians are best able to evaluate. This idea is that sorrow, bereavement, severe grief, and depression have biological differences and that there is a range of different emotions in which normal sorrow and sadness are situated at one end and more severe depressive responses at the other end [72].

Conversely, several prominent members of the psychiatric and medical community have voiced their criticisms about these changes. In fact, quite a debate has ensued around the narrower and broader levels of both the research studies that support the removal of the *bereavement exclusion* as well as the consequences for the new criteria. There are three major criticisms of the removal of the *bereavement exclusion* in the DSM-5. First, longitudinal data indicate that those who experienced a single, brief depressive episode due to bereavement had unique symptoms and no greater risk for future depression compared to those who experience other types of depression [52]. Similarly, a comparison of bereavement-related depression and depression from other sources revealed that there are distinct differences between uncomplicated and complicated depression for both bereavement and other losses [73]. These two studies support the previous criteria in the DSM-IV of the *bereavement exclusion* as a way to distinguish between different types of depression and thus do not support the elimination of the *bereavement exclusion* in the DSM-5. Second, there have also been important criticisms of the studies cited as evidence for the *bereavement exclusion* changes in the DSM-5. Some research compared all bereavement-related depression to depressions caused from other life stressors [64]. Critics of the changes considered this type of comparison problematic because they believed there needed to be a distinction between uncomplicated and complicated reactions to grief in the bereavement-related depression group because the *bereavement exclusion* did in fact

distinguish between the two categories [74]. In addition, the international studies by Kessing et al. [70], Corruble et al. [68], and Karam et al. [69] that were previously mentioned were also criticized because they were believed to have either not correctly tested the *bereavement exclusion* or used samples that were too small to draw any worthy conclusions [74]. The third major criticism to the removal of the *bereavement exclusion* is that the *bereavement exclusion* already considered severe expressions of grief. About 10–15% of bereaved individuals reportedly experience severe expressions of grief [75]. It is these individuals to which the new DSM targets [66]; many proponents of the changes argue that the DSM-5 will allow health professionals to identify bereaved individuals who need help. Yet, the criteria to help these individuals who experience severe grief already existed in the DSM-IV [76].

The major arguments for retaining or eliminating the exclusion suggest that although the distinction between severe “normal” grief and depressive illness can be blurry, the two “sides” of the argument would actually treat patients in a very similar manner. Patients seen as experiencing normal grief might be treated for symptoms like insomnia but would be given reassurance that their painful state was “normal” and would resolve over time, while patients seen as suffering from depressive illness would be treated with psychotherapy, medication, or a combination thereof [77].

(c) DSM-5 Trauma- and Stressor-Related Disorders Chapter

The Trauma- and Stressor-related disorders chapter is a new DSM-5 chapter including disorders in which exposure to a traumatic or stressful event is listed explicitly as a diagnostic criterion. These include reactive attachment disorder, disinhibited social engagement disorder, acute stress disorder (ASD), post-traumatic stress disorder (PTSD), and adjustment disorders. When the death of a loved one occurred in unnatural, violent, or accidental way and not due to natural causes, individuals can develop PTSD or acute stress disorder (e.g. death due to natural causes does not qualify). Particularly PTSD is described as a disorder with

varied clinical presentations. Chapter 2 describes in detail the interplay between grief and post-traumatic stress, and Chap. 5 also reviews diagnostic criteria for acute stress disorder and post-traumatic stress disorder.

The essential feature of ASD is the development of characteristic symptoms lasting from 3 days to 1 month following exposure to one or more traumatic events. The clinical presentation of acute stress disorder may vary by individual but typically involves an anxiety response that includes some form of re-experiencing of or reactivity to the traumatic event. In some individuals, a dissociative or detached presentation can predominate, although these individuals typically will also display strong emotional or physiological reactivity in response to trauma reminders. In other individuals, there can be a strong anger response in which reactivity is characterized by irritable or possibly aggressive responses. The full clinical picture must be present for at least 3 days after the traumatic event and can be diagnosed only up to 1 month after the event. Symptoms that occur immediately after the event but resolve in less than 3 days would not meet criteria for acute stress disorder. The traumatic event can be re-experienced in various ways. Commonly, the individual has recurrent and intrusive recollections of the event (Criterion B1). The recollections are spontaneous or triggered recurrent memories of the event that usually occur in response to a stimulus that is reminiscent of the traumatic experience. These intrusive memories often include sensory, emotional, or physiological components. Distressing dreams may contain themes that are representative of or thematically related to the major threats involved in the traumatic event. Dissociative states may last from a few seconds to several hours, or even days, during which components of the event are relived and the individual behaves as though experiencing the event at that moment. While dissociative responses are common during a traumatic event, only dissociative responses that persist beyond 3 days after trauma exposure are considered for the diagnosis of acute stress disorder. Some individuals with the disorder do not have intrusive

memories of the event itself, but instead experience intense psychological distress or physiological reactivity when they are exposed to triggering events that resemble or symbolize an aspect of the traumatic event. The individual may have a persistent inability to feel positive emotions but can experience negative emotions such as fear, sadness, anger, guilt, or shame. Alterations in awareness can include depersonalization, a detached sense of oneself, or derealization, having a distorted view of one's surroundings. Some individuals also report an inability to remember an important aspect of the traumatic event that was presumably encoded. Stimuli associated with the trauma are persistently avoided. The individual may refuse to discuss the traumatic experience or may engage in avoidance strategies to minimize awareness of emotional reactions. It is very common for individuals with acute stress disorder to experience problems with sleep onset and maintenance, which may be associated with nightmares or with generalized elevated arousal that prevents adequate sleep. Individuals with acute stress disorder may be quick tempered and may even engage in aggressive verbal and/or physical behaviour with little provocation. Acute stress disorder is often characterized by a heightened sensitivity to potential threats. Concentration difficulties, including difficulty remembering daily events or attending to focused tasks, are commonly reported. Individuals with acute stress disorder may be very reactive to unexpected stimuli, displaying a heightened startle response or jumpiness to loud noises or unexpected movements.

In PTSD, the traumatic event can be re-experienced in various ways. Commonly, the individual has recurrent, involuntary, and intrusive recollections of the event (Criterion B1). A common re-experiencing symptom is distressing dreams that replay the event itself or that are representative or thematically related to the major threats involved in the traumatic event (Criterion B2). The individual may experience dissociative states that last from a few seconds to several hours or even days, during which components of the event are relived and the individual behaves as if the event were

occurring at that moment (Criterion B3). Intense psychological distress (Criterion B4) or physiological reactivity (Criterion B5) often occurs when the individual is exposed to triggering events that resemble or symbolize an aspect of the traumatic event. The individual commonly makes deliberate efforts to avoid thoughts, memories, feelings, or talking about the traumatic event (Criterion C1) and to avoid activities, objects, situations, or people who arouse recollections of it (Criterion C2). Negative alterations in cognitions or mood associated with the event begin or worsen after exposure to the event. These negative alterations can take various forms, including an inability to remember an important aspect of the traumatic event (Criterion D1). Another form is persistent and exaggerated negative expectations regarding important aspects of life applied to oneself, others, or they may manifest as a negative change in perceived identity since the trauma (Criterion D2). Individuals with PTSD may have persistent erroneous cognitions about the causes of the traumatic event that lead them to blame themselves or others (Criterion D3). A persistent negative mood state (e.g. fear, horror, anger, guilt, shame) either began or worsened after exposure to the event (Criterion D4). The individual may experience markedly diminished interest or participation in previously enjoyed activities (Criterion D5), feeling detached or estranged from other people (Criterion D6), or a persistent inability to feel positive emotions (Criterion D7). Individuals with PTSD may be quick tempered and may even engage in aggressive verbal and/or physical behaviour with little or no provocation (Criterion E1). They may also engage in reckless or self-destructive behaviour such as dangerous driving, excessive alcohol or drug use, or self-injurious or suicidal behaviour (Criterion E2). PTSD is often characterized by a heightened sensitivity to potential threats, including those that are related to the traumatic experience and those not related to the traumatic event (Criterion E3). Individuals with PTSD may be very reactive to unexpected stimuli, displaying a heightened startle response, or jumpiness, to loud noises or unexpected movements (Criterion E4).

Concentration difficulties, including difficulty remembering daily events (e.g. forgetting one's telephone number) or attending to focused tasks, are commonly reported (Criterion E5). Problems with sleep onset and maintenance are common and may be associated with nightmares and safety concerns or with generalized elevated arousal that interferes with adequate sleep (Criterion E6). Some individuals also experience persistent dissociative symptoms of detachment from their bodies (depersonalization) or the world around them (derealization); this is reflected in the "with dissociative symptoms" specifier.

The presence of emotional or behavioural symptoms in response to an identifiable stressor is the essential feature of adjustment disorder (Criterion A). Adjustment disorders may be diagnosed following the death of a loved one when the intensity, quality, or persistence of grief reactions exceeds what normally might be expected, when cultural, religious, or age-appropriate norms are taken into account. DSM-5 specifies that PCBD represents a more specific set of bereavement-related symptoms.

Differences Between CG, PGD, and PCBD

To date, the diagnostic criteria for CG and PGD have the most clinical and empirical support. Both CG and PGD diagnostic criteria are based on data derived from several studies and present their own strengths and weaknesses, leading to some intense scientific debate around the specific criteria to be retained.

On one hand CG criteria were developed using a large and representative clinical sample of 782 subjects with CG ($n = 304$), mood or anxiety disorders ($n = 383$), or a normal grief. Item response theory based statistical analyses were used to determine these criteria and were confirmed by expert clinical consensus. Two studies on large clinical and community samples were recently conducted to test this diagnostic construct. The first study tested the performance of CG

and PGD criteria in a sample of bereaved individuals seeking help for impairing grief ($n = 240$) or for mood or anxiety disorders ($n = 86$). CG criteria diagnosed 99.6% of the clinical cases while PGD ones identified only 59.6%. All subjects with primary mood or anxiety disorders were excluded by both CG and PGD criteria. Furthermore, bereaved individuals who endorsed low grief scores were not misidentified by CG or PGD [50]. In the second study, CG and PGD criteria were utilized in a community sample of 1732 participants who experienced the death of a US military relative. Again, CG criteria diagnosed 91.9% of the participants who reported high grief symptoms and impairment rating compared with 59.3% identified by PGD. Subjects with low grief symptoms, including those with major depression, were excluded by CG and PGD criteria [49]. These results showed how CG criteria present a greater sensitivity respect to PGD in the identification of subjects with high grief symptom rates and who reported a significant treatment response as those meeting PGD criteria [78].

On the other hand, PGD criteria were validated utilizing data obtained from the Yale Bereavement Study, a large field trial conducted on 291 bereaved individuals. Combinatoric analyses were used to identify the most sensitive and specific diagnostic criteria from symptoms proposed by the consensus panel [21]. More recently, Maciejewski et al. [25] evaluated 268 participants of the Yale Bereavement Study to compare the performance of PGD, CG, and PCBD diagnostic criteria sets. Results showed no significant differences between PGD and PCBD in diagnostic specificity and predictive validity, suggesting that they identify the same disorder. Conversely, CG criteria presented higher estimate rate of the disorder (30% vs. 10% of PGD and PCBD), a lower diagnostic specificity (37.0% vs. 98.3% of PGD and 95.0% of PCBD), and lack of predictive validity. Based on the data reported above the authors suggested that PGD has a greater specificity and describes more accurately the pathological condition, without the risk of pathologizing normal grief reaction [79].

Taken together, this suggests that the CG diagnostic criteria set may allow more individuals to be diagnosed and receive treatment, while the PGD diagnostic criteria may be more conservative. To date, this topic is still the object of intense scientific debate [78, 79] and might partially reflect, at a certain level, the tension between the different aims of all diagnostic classifications systems: being useful to clinicians, patients, researchers, insurance companies, while also accurately depicting psychiatric illnesses.

The differences in terminology and the absence of agreement between the two workgroups have led the DSM-5 to introduce the diagnostic criteria set for PCBD. As described above, the time frame is different compared to CG and PGD (12 vs. 6 months), as well as the number of symptoms required for criteria B (core symptoms) and C (associated symptoms). According to PGD yearning/separation distress have to be present as the sole qualifying symptom (criterion B), plus five of nine cognitive, emotional, and behavioural symptoms (criterion C). The CG diagnosis requires one among yearning or longing for the deceased, intense loneliness, feeling that life is unbearable since the death, and frequent preoccupying thoughts of the deceased (criteria B), and two of eight cognitive, emotional, and behavioural symptoms (criterion C). Interestingly, PCBD adds to diagnostic criteria proposed for CG and PGD, a new core symptom: intense sorrow and emotional pain in response to the death. This is interesting as already, early conceptualizations of grief emphasized a central role to emotional pain [80], and a recent network analysis study supported it as the most central symptom of grief psychopathology [81].

Conclusion

Grief has been widely studied in the last decades. These great amounts of data have evidenced the psychological and behavioural manifestations of bereaved people. The clinical features and the core symptoms of pathological grief reaction have also

been explored and debated. In this regard, the literature shows us two similar but in some way different models of pathological grief, CG and PGD, validated in clinical studies by specific questionnaires. Despite the strong evidence supporting a specific disorder related to grief, the absence of consensus in terminology and diagnostic criteria have led the DSM-5 group to introduce a new different and not validated disorder only in the section 3 of the manual “*condition for further studies*”: PCBD. The authors of the DSM seem to have instead focused their attention on conditions that historically have been found present in the aftermath of the loss of a loved one, but that are not specific to bereavement, from depression with the removal of the *bereavement exclusion*, to the development of a new specific chapter for *trauma and stress related disorders*. Currently, a lively debate between the different theories on grief is still ongoing, and evidences supporting one or the other are constantly updated. In the future, the introduction of a unique globally accepted model of pathological grief in the international classifications will change the current prospective of the public and expert opinion of this issue.

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