

## Complicated Grief and the End-of-Life: Risk Factors and Treatment Considerations

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*Some 18 months after the death of her husband, Mary, age 62, describes herself as “drowning in a sea of grief.” Far from moving toward some form of recovery, she experiences herself as “stuck” in a futile protest against the impossibility of living without John, who had been the “compass” for her life for the past two decades. Without the special caring, attunement and structure he provided her, Mary feels “disoriented,” “unreal,” as if his death is “just some sort of terrible joke” on the part of a cruel or neglectful God. John’s relatively fast demise from an aggressive cancer gave her little time to adapt to the harsh reality of his impending loss, but Mary confesses that she spent the majority of this “warning period” actively resisting the knowledge of his eventual death and “struggling” with other family members regarding whether to continue aggressive treatment in the face of “unrealistic hope” offered by his doctors. Now, she feels deeply lonely and “cut off” from others, with the exception of her concerned adult daughter, and is caught up in an angry dispute with John’s children by another marriage about the estate. Tearfully, she describes how she has “no purpose for living” since his death, and although she is not actively suicidal, she finds herself wishing that it were she, rather than he, who had died.*

Few people go through life without experiencing grief as a result of the loss of a loved one, with each death leaving on average six or more significant others in its wake (McDaid, Trowman, Golder, Hawton, & Sowden, 2008). Bereavement, however, is variable in both its course and its consequences. In terms of duration, significant grief may be limited to a few weeks in the case of individuals who are highly resilient (Bonanno & Kaltman, 2001), though a more normative trajectory involves readjustment to life over the course of a few years (Bonanno, Wortman, & Nesse, 2004). On the extreme end of the continuum, *complicated grief* (CG; Prigerson et al., 1995; Shear et al.,

2011) or *prolonged grief disorder* (PGD; Boelen & Prigerson, 2007) -- a reaction to loss that is marked by protracted, debilitating, sometimes life-threatening symptomatology (Latham & Prigerson, 2004) -- affects approximately 10-15% of the population who are not bereaved as a result of violence (Prigerson, et al., 1995), though a far higher incidence of complication characterizes those bereaved because of violence (McDevitt-Murphy, Neimeyer, Burke, & Williams, in press); Shear, Jackson, Essock, Donahue, & Felton, 2006), as well as those who lose children (Keesee, Currier, & Neimeyer, 2008). Our goal in the present chapter is to draw attention to features of complicated grief that should concern clinicians working with families grieving the death of a loved one, and to underscore empirically supported risk factors for this extended and debilitating condition. We will also note recent work that attempts to bridge challenges encountered in the course of end-of-life care with those evident in bereavement among surviving family members. Finally, we will discuss some interventions in the course of palliative and hospice care that hold promise for mitigating suffering of family members following their loved ones' death, and will close by noting some principles and practices that can inform grief therapy for those whose grief is extended and life-damaging.

### **Features of Complicated Grief**

As exemplified in Mary's case, complicated grief (CG) is characterized by a relentless period of profound grieving that continues for at least six months beyond the death of the loved one, in which the survivor suffers marked and disruptive separation distress and psychologically disturbing and intrusive thoughts of the deceased. Additionally, CG frequently entails a sense of emptiness and meaninglessness about life and/or the future, trouble accepting the reality of the loss, and difficulty moving forward in making a life without the deceased (Holland, Neimeyer, Boelen, & Prigerson, 2009; Prigerson & Jacobs, 2001). Stroebe, Schut, and Stroebe (2007) found that grievers, especially spouses, have an increased risk of early mortality merely as a result of being

bereaved, and other investigators have found CG in particular to predict a variety of concerning conditions, including impaired quality of life and social functioning, substance abuse, immune dysfunction, cardiovascular illness, and suicide (Latham & Prigerson, 2004; Prigerson et al., 2009); Prigerson, Beirhals, Kasl, Reynolds, & al., 1997). Table 1 summarizes defining symptoms of CG. Clinicians should be alerted to these symptoms as they evaluate the longer-term adaptation of clients to the loss of a loved one, as both self-report (Keesee et al., 2008) and neurophysiological (O'Connor et al., 2008) data suggest that time alone does little to assuage CG symptomatology. Once identified, however, prolonged grief is clearly amenable to treatment (Shear, Simon, et al., 2011).

### **Risk Factors for Complicated Grief**

Who is at risk for complicated grief after a loss? To address this question, clinicians need to consider both fixed or relatively enduring characteristics of the survivor and shifting or circumstantial factors that bear on his or her ability to adapt to the death of a loved one. In the first category, each of us brings to loss aspects of ourselves such as gender, ethnicity, prior losses, attachment styles, and the role our deceased played in our lives (i.e., mother). Here, we will summarize our recent review of prospective risk factors for complicated grief (Burke & Neimeyer, 2012), focusing on enduring individual differences associated with complications in bereavement. Following this, we will turn to circumstances of the death or treatment in the end-of-life (EOL) period associated with poorer long-term outcomes for survivors, as well as factors observable in the course of bereavement that can become causes of concern, or alternatively suggest resilience in the wake of loss.

#### ***Predisposing Factors***

***Gender differences.*** In terms of gender, Lang and Gottlieb (1993) found in their study of parents who had lost infants that mothers experienced higher levels of grief than did fathers.

Likewise, although Spooen, Henderick, and Jannes (2000) found no difference in terms of the

general psychological distress of 85 mothers and fathers bereaved by motor vehicle accidents, women did have higher levels of CG than did men. In a study of 151 Pakistani psychiatric patients, Prigerson et al. (2002) found that women had higher rates of CG than men; and, in a study of bereaved parents, Keesee et al. (2008) found that mothers had more grief than fathers but not more CG. Although gender differences are not always observed in bereavement adaptation, when they are women tend to display greater susceptibility to separation distress than men.

***Kinship relation to the deceased.*** Kinship (whether the deceased is one's spouse, parent, child, sibling, etc.) has been linked to intensified grief (Boelen, van den Bout, & van den Hout, 2003). For example, a large study ( $N = 1670$ ) with young adult grieverers revealed a main effect for kinship in predicting CG, such that individuals bereft by the death of an immediate family member had higher grief than those who lost more distant family members (Laurie & Neimeyer, 2008). Likewise, Cleiren (1993) found that kinship remained the most powerful predictor of grief even 14 months post loss -- spouses and parents suffered more in terms of grief than did adult children or siblings. And, consistently, mothers suffered most of all, even when controlling for other demographic factors. Similarly, Prigerson et al. (2002) compared types of relationships and found differences in CG levels, such that spouses and parents ( $N = 151$ ) had much higher rates of CG than did other kinship types. Yet, other studies (Bonanno, Papa, Lalande, Zhang, & Noll, 2005) detected no initial differences until 14 months post-loss, when parents' CG scores were higher than those of spouses.

***Race and ethnicity.*** Several studies have noted racial or ethnic differences in susceptibility to bereavement complication. Goldsmith and colleagues' (2008) two-sample study (316 bereaved individuals and 222 cancer patients and their caregivers), Laurie and Neimeyer's (2008) sample of 1670 bereaved college students (940 Caucasians and 641 African Americans), and Neimeyer, Baldwin, and Gillies' (2006) study of 506 young adults all found higher levels of CG in African

Americans than in Caucasians. Another study compared racial groups in a sample of 252 HIV-infected griever and found that minorities (African Americans and Hispanics) reported more grief than Caucasians (Tarakeshwar, Hansen, Kochman, & Sikkema, 2005). However, a different study that examined race and CG in a sample of older, bereaved spouses found no difference in levels of yearning or grief when comparing African Americans ( $n = 33$ ) and Caucasians ( $n = 177$ ; (Carr, 2004). Likewise, Cruz et al. (2007) found no differences among members of the same two ethnic groups presenting for CG therapy. Finally, in one of the rare international studies, (Bonanno, et al., 2005) research on bereaved parents ( $n = 52$ ) and spouses ( $n = 90$ ) from the People's Republic of China and the U.S., assessed longitudinally at 4 and 18 months post loss, revealed that the Chinese sample had grief scores that were initially higher than those found in the U.S. sample, but later were lower than those of their American counterparts. In summary, many but not all studies of racial or ethnic differences in adaptation to bereavement suggest greater risk for ethnic minorities, at least within the United States, in keeping with broader research on mental healthcare disparities for different communities. Such findings shed little light, however, on factors that account for these disparities, underscoring the importance of studying cultural as well as individual factors that promote or impede adaptation (Rosenblatt & Wallace, 2005).

***Attachment styles.*** In research examining attachment styles, van der Houwen et al.'s (2010) study of 195 bereaved individuals indicated that avoidant but not anxious attachment signaled higher levels of CG. Brown, Neese, House, and Utz's (2009) study ( $n = 103$ ) found at 6, 24, and 48 months that pre-loss insecure attachment style and post-loss grief were related. In two separate studies of 219 bereaved parents, Wijngaards-de Meij et al. (2007a; 2007b) found that avoidant/anxious attachment styles explained 13% of the variance in CG levels; and yet, other studies found no association between avoidant/dismissive attachment and grief (Bonanno et al., 2002).

Although more research is needed, a relation between the mourner's pre-loss dependency upon his or her spouse and subsequent grief also has been reported. Specifically, results from one study (Bonanno et al., (2002) prospectively linked pre-loss spousal dependency with CG, but not with resilience. Findings from another study (Carr, 2004), showed that spousal dependency predicted increased levels of grief-related despair. Yet, other studies show no such association (Cleiren, 1993).

### ***Death-related risk factors and end-of-life considerations***

Several studies (Gamino, Sewell, & Easterling, 2000; Rando, 1983) have linked the number of other losses experienced by the survivor with levels of grief. Post-loss bereavement can be influenced by pre-death factors such as quantity and quality of medical care, caregiver burden, acceptance of an anticipated death and/or anticipatory grieving, end-of-life decision-making, one's religious or spiritual beliefs, how the death occurred (e.g., following a long illness vs. homicide) and other factors related to the final moments of life or shortly after (e.g., death notification).

***Caregiver burden, acceptance, and anticipatory grief.*** The emotional and physical toll of caring for a dying loved one cannot be overstated, especially as it pertains to subsequent bereavement. In their six-wave longitudinal study of the impact of caregiving on depressive symptoms over time, (Aneshensel, Botticello, & Yamamoto-Mitani, 2004) found that caregiver burden significantly increased the probability of postloss depressive symptoms and grief. Conversely, pre-death grief work can facilitate the mourning process. Examining data from 123 members of various online bereavement support groups, (Metzger & Gray, 2008) discovered that levels of pre-loss acceptance predicted less post-loss CG, even when time since loss and closeness to the deceased were held constant. However, this finding held true only in cases where griever fully expected that their loved one would die. No such association was found between pre-loss acceptance and CG levels in

survivors who did not foresee the death. McCarthy and associates conducted a study to examine rates of CG in 58 parents bereaved of a child to cancer (McCarthy et al., 2010). They found that rates of CG were predicted by less time since loss, preparedness for the death, economic hardship (as a result of the illness), and the parent's estimation of both the oncologist's care and the child's quality of life in his or her final days.

Moreover, research has shown that bereft individuals who have trouble adjusting to their loss in terms of grief may be less likely to have engaged in anticipatory grief behaviors (Rando, 1983). For example, Rando found in her study of 54 parents bereaved by their child's cancer that when anticipatory grieving was done prior to the death, less disordered grieving occurred afterward.

***End-of-life medical care, ethics, and decision-making.*** One study of 332 caregivers who had lost their loved one on average six months prior found that aggressive medical intervention (e.g., admission to an intensive care unit, ventilation, resuscitation, chemotherapy, or use of a feeding tube) given to the patient prior to death predicted aspects of grief such as regret and feeling unprepared for the death (Wright et al., 2008).

From his review, Doka ascertained that end-of-life ethics and decisions can aid or prevent successful loss accommodation, sometimes simultaneously (Doka, 2005). Examples of instances where end-of-life decision-making tended to predict CG included: terminating treatment or stopping heroic measures, family conflicts surrounding end-of-life care options, and torment related to the loved one's final moments (i.e., did he or she suffer needlessly due to thirst, starvation, or ineffective attempts at pain control). Ambivalence in itself has been found to increase grief, partly because it is so pervasive surrounding the death. For example, family members or caregivers may concomitantly wish for the loved one's suffering to end while at the same time wish to extend his or her life as long as possible (Doka, 2005). Similarly, it has been suggested that a highly ambivalent or poor pre-loss

relationship between the deceased and survivor, where feelings were equally positive and negative, can intensify the post-loss grief reaction (Feigelman, Jordan, & Gorman, 2009; Wordan, 2002).

***Cause and place of death.*** Although exceptions exist (Prigerson et al., 2002), a growing body of studies indicates that violent death loss (e.g., homicide, suicide, or fatal accident) tends to elicit a more intense and complicated bereavement than deaths due to illness. For instance, in a study of Bosnian refugees, the strongest risk factor for CG occurred when one family member experienced the traumatic loss of another (Momartin, Silove, Manicavasagar, & Steel, 2004). Keesee et al. (2008) examined the full continuum of grief responses in a comparison study of parents bereaved as a result of violence and parents bereaved by other means, and found that violent death loss produced higher levels of grief. Other longitudinal studies comparing suicide and MVA to extended illness (Cleiren, 1993), or survivors of illness to homicide, suicide, and accident (Gamino, Sewell, & Easterling, 2000) found similar results—that violently bereaved individuals suffered more in terms of grief. Finally, in comparing type of death in 1723 bereaved young adults, Currier, Holland, Coleman, and Neimeyer (2007) discovered that violent, unnatural death (accident, suicide, and homicide) was associated with worse bereavement outcome in terms of grief than death by other means (i.e., natural, anticipated deaths such as lengthy illness, or natural, sudden deaths such as heart attack). Although types of violent death loss (accident, suicide, or homicide) were not significantly different from one another, CG scores for survivors of violent death loss were significantly elevated over those of survivors of non-violent loss; specifically, loss through homicide and accident was associated with more severe grief than was loss through sudden yet natural means (e.g., heart attack). Generally speaking, in comparison to all other types of death, homicide predicted poorer outcome in terms of grief.

In terms of where the death occurred, a study of 342 cancer caregivers found that mourners

whose loved one died in the hospital were 22% more susceptible to suffering from CG than caregivers whose loved one died at home under the care of hospice (Wright et al., 2010).

***Peri-event variables.*** Although research is limited, a consistent association has been found between peri-death factors and grief severity. One study of 210 suicide survivors found that although the method of suicide (e.g., gunshot) had little bearing on grief, finding or seeing the loved one's body immediately after the death significantly increased grief levels, especially for women (Callahan, 2000). Another comparison study of suicide survivors found that the greatest predictor of grief was finding the body immediately following the death (Feigelman, Jordan, & Gorman, 2009); and, specifically, that elevated grief levels were more closely associated with griever's who saw or found the body than in survivors who had not seen the body following the suicide. Other studies (e.g., Spoooren et al., 2000) have examined aspects surrounding motor vehicle accident deaths of children, such as how and what the parents are told. They found that dissatisfaction with information given about the event and with material assistance predicted increased CG levels.

***Religion and spirituality.*** Prospective studies of the role of religion and spirituality in bereavement have produced mixed findings. For instance, one study showed that even though church attendance was unrelated, the greater importance placed on religious/spiritual beliefs before the loss meant that griever's had lower levels of grief at 6 and 18 months post-loss (Brown et al., 2009). Other findings revealed the opposite, however. When 65 women who birthed a full-term baby were compared to 62 women who had terminated their pregnancy, individuals who valued their faith more experienced more severe grief than those who valued their faith less (Kersting et al., 2007). In their correlational study, Easterling et al. (2000) discovered an association between griever's understanding of events that increase belief in God's existence and/or beliefs about their relationship with God and lower levels of grief. Other research (Bonanno et al., 2002) showed that individuals

who fared best believed in a just world and were also more accepting of their loss.

Considering Mary's case in light of the pre-loss risk factors reviewed above, several features of her background, as well as features surrounding John's treatment and death, increased the probability of her responding to his loss with greater complication. These included (1) her gender, (2) her loss of her husband, (3) the threat this posed to a security enhancing attachment, (4) her low acceptance of his prognosis, (5) his death in the relatively impersonal and technologically dominated hospital environment, and (6) the considerable ambivalence and conflict in the family regarding the course of his treatment. Table 2 provides a convenient checklist of risk factors for complicated or intensified grief observable before the death of a loved one, which in combination can help identify family members in need of heightened support during the end-of-life period.

### ***Risk Factors in Bereavement***

Factors subsequent to the loss itself, such as the amount of time since the death, quantity and quality of social support, beliefs about whether or not the death could have been prevented, the search for and success at meaning making, and other beliefs or fears about how well one is doing or will fare in the days following have been shown to predict loss accommodation.

***Initial grief responses.*** In their study comparing types of violent death loss, Feigelman, et al. (2009) found that time since loss was the strongest predictor of grief difficulties, such that survivors who were most recently bereaved suffered the most. Survivors whose loved one died after a first-time suicide attempt rather than after a history of multiple attempts also suffered more grief.

Gamino, et al. (2000) showed that bereaved individuals who maintained the belief that the death was preventable fared more poorly than those who did not. Doka (2005) echoed this, but also added that a lack of forewarning in terms of projecting that the death was imminent also prompted a more severe grief reaction.

***Bereavement-associated negative cognitions.*** Boelen, van den Bout, and van den Hout (2006) measured early-bereavement thoughts (1- 4 months post loss) that the griever held about his or her *self, life, future, or threatening interpretations of grief* (e.g., “If I would fully realize what the death of \_\_\_\_ means, I would go crazy”) and found that each individually predicted CG as bereavement progressed (7-10 months post loss). Moreover, negative cognitions specifically related to the *future* (e.g., “In the future, I will never become really happy anymore”) prospectively predicted CG at the third assessment period, well over a year after the death (16-19 months post loss). The same held true in relation to an interaction effect of *threatening interpretations X avoidance of the reality of the loss* predicting CG at Time 3.

***Searching for meaning and sense making.*** Results of a prospective longitudinal study of older, bereaved adults (Coleman & Neimeyer, 2010) suggest that a more intense effort to find meaning in the loss was predictive of higher levels of grief. Even four years after the death, grievers who could not make sense of the loss early on (6 and 18 months post-loss) still struggled with high grief distress. In contrast, those who could find a way to make sense of their loss experienced a greater sense of overall well-being—showing interest and excitement in life, and a sense of personal accomplishment (see also Davis, Wortman, Lehman, & Silver, 2000). Importantly, high separation distress early in bereavement also prospectively predicted spiritual struggle, suggesting that a vicious circle can be set in motion in which intense grief can exacerbate problems with spiritual sense making in the wake of loss (Burke, Neimeyer, McDevitt-Murphy, Ippolito, & Roberts, 2011).

***Social support.*** Rando (1983) showed that bereaved parents with greater amounts of support suffered less grief. Laurie and Neimeyer (2008) found in their comparison study of young-adult grievers that African Americans spent less time talking about their losses than did Caucasians and that less time discussing the loss was associated with increased grief scores. Identification of

modifiable risk factors, such as social support, can guide the development of relevant secondary or tertiary interventions. For instance, armed with the knowledge that poor social support (i.e., negative interactions) poses risks to bereavement adaptation (Burke, Neimeyer, & McDevitt-Murphy, 2010), healthcare professionals in end-of-life contexts could assess families' social support before bereavement begins, with an eye toward preventive intervention.

Mary's case exemplifies most of these features associated with intense and prolonged grief reactions, including (1) strong initial responses to her husband's death; (2) little warning of his death given the brief period since his diagnosis; (3) her sense that the death could have been prevented by earlier detection of his symptoms; (4) her fatalism regarding the purposelessness and joylessness of a future without John; (5) her avoidance of the reality of his death, as in her insistence in washing his clothes repeatedly, as if he were merely away on a trip; (6) her anguished search for meaning and struggle with God's intentions in taking his life; and (7) the low social support she experienced, as a function of withdrawing from many relationships and isolating herself in her grief. Clinical Pearl 1 provides a convenient list of factors observable in bereavement that predict more intense and prolonged grieving for survivors, and associated principles to guide intervention.

### **Available Treatments for Bereaved Individuals**

Grieving is the natural, normal, and often necessary response of humans to loss. Thus, professional treatment is not always required, as most bereaved individuals adapt well over time, given their own resources and those of their families and communities. However, when grief is complicated and prolonged, evidence suggests that intervention is both indicated and efficacious (Currier, Neimeyer, & Berman, 2008). Fortunately, several research-informed treatments exist, both for use prior to the loss and afterward. The following are examples of grief-specific interventions.

**Focused Family Grief Therapy (FFGT; Kissane & Bloch, 2002).** FFGT is a pre-loss

intervention that screens “at risk” families into the intervention that spans 6-18 months, beginning several months before the loved one dies and continuing through bereavement for 6-12 sessions, depending upon the family’s distress level. Based on the Family Relationships Index (FRI), families are classified as either well-functioning (i.e., *supportive*—showing a high level of cohesion, or *conflict resolving*—permitting and accepting each others’ differences and dealing with discord constructively) or dysfunctional (*hostile*—families characterized by high conflict, low cohesion, and poor expressiveness, or *sullen*—families characterized by poor communication, depression, and muted anger). A final *intermediate* group shows some impairment in communication and teamwork, although conflict is less intense than in the hostile group (Kissane & Hooghe, 2011). According to Kissane and Zaider (2011), over half of the families of dying cancer patients are well-functioning and thus do not need therapy; however, immediately following the death, approximately 20% of families fall into the dysfunctional categories and are in need of specialized therapeutic attention. Importantly, however, Kissane and Bloch (2002) have also found that although sullen and intermediate families respond well to family therapy, hostile families do not, and instead deteriorate in conjoint sessions. For this reason, the latter families, marked by stormy and unresolved conflict, are better offered individual treatment, where each member’s unique needs can be assessed and addressed without the compounded distress generated by family sessions.

Kissane and Bloch (2002) outlined a number of key therapeutic processes and challenges inherent to the family engaged in FFGT, including inviting a discussion of death into the room, by speaking candidly about the illness and its prognosis. Specifically, therapists are urged to: 1) encourage families to view the loss in hypothetical rather than impending terms, and 2) maintain a neutral stance when it comes to juxtaposing hopeful family members with those who are already experiencing anticipatory grief reactions. Preserving an impartial position enables the clinician to

serve the family dispassionately in spite of their discrepant coping styles. Other families will need the therapist's active involvement for them to engage in conversation at all—even to the point of the therapist inviting each member individually. Likewise, therapy conducted in the home must by necessity include clear boundaries in order to establish a therapeutic environment minus the distraction caused by TV, phone calls, and other factors. In addition, cross-cultural challenges surface when individual members with distinct expectations about the dying process attempt to mesh as a family unit. Thus, prior to death, the clinician may invite the family to decide together exactly what, how, and how much they will discuss. Families with young children bereft of a parent might need special attention. Kissane and Zaider (2011; Kissane & Hooghe, 2011) claim that when a model that encourages candid expression of thoughts and feelings is used it also strengthens the surviving parent's belief that he or she can manage as a single parent. However, great sensitivity is advised in pursuing such conversations, respecting the wisdom of both talking and *not talking*, a means of regulating difficult emotions within and between family members (Kissane & Hooghe, 2011). Clinical Pearl 2 summarizes several of these recommendations for clinical practice.

**Complicated Grief Treatment** (CGT; Shear, Frank, Houch, & Reynolds, 2005) is an individual intervention specifically designed to address CG symptoms in bereaved individuals. It consists of ten modules that include psychoeducation about grief work as well as experientially powerful engagement with one's own distress over the loss. *Imaginal revisiting* of the story of the death, in which the griever verbally shares his or her detailed account of the death event from the moment of notification until the burial, is a key component of CGT. Such revisiting typically elevates the survivor's initial distress level considerably, with the goal of promoting mastery of the distressing experience in the compassionate presence of the therapist. Similarly, *situational revisiting* challenges behaviors and cognitions that reinforce the perpetual avoidance of places,

people, or events that cause the griever significant distress in bereavement but were once enjoyed freely, thereby promoting fuller engagement with life. CGT also includes *imaginal conversation* between the client and the deceased, with the therapist helping the client to participate in a two-way symbolic conversation with the deceased loved one to resolve troubling concerns that haunt the relationship, such as caregiver guilt arising from the circumstances of the death. Additional modules of the therapy tap into both positive and negative memories that the survivor has in relation to the deceased loved one, in what is referred to as *emotional memory work*, and helps him or her to revise life goals and meaningful relationships as he or she engages in *future planning*. Although CGT is principally an individual intervention, it also commonly includes inviting a trusted family member or friend to join the client and therapist in one or more sessions as a means of showing support of CGT for the griever (Shear, Boelen, & Neimeyer, 2011; Shear, Gorscak, & Simon, 2006). To test the efficacy of this multi-component intervention, Shear and her team (2005) conducted a randomized control trial with 95 griever, comparing it to interpersonal psychotherapy (IPT), an evidence-based treatment that has been found efficacious for treating depression. CGT reduced the incidence of CG by 51%, compared to 28% for IPT, and was particularly efficacious for those suffering violent death loss.

**Cognitive Behavioral Therapy (CBT) for CG** (Boelen, van den Hout, & van den Bout, 2006) is grounded in the assumption that griever need to integrate the loss into their existing autobiographical knowledge, change patterns of thinking that are unhelpful, and replace unhelpful avoidance strategies with helpful actions and coping strategies. As with CGT, one important component of CBT is *exposure*. Clients may narrate their loss experience in verbal or written form, expressing the most difficult and painful aspects of the death. Subsequently, griever are instructed to cease behaviors that are considered compulsive (e.g., asking “why” the

death happened, visiting the gravesite). Related CBT strategies include confrontation of anxious avoidance of people, situations, and thoughts based on predictions that the pain of the loss in some way will be too much to endure, so as to build more adaptive behaviors.

A second component of CBT is *cognitive restructuring*—the systematic identification and reorganization of one's thoughts, and the substitution of unhelpful cognitions with helpful ones. For example, hopeless statements about one's future might be challenged with, "What might be the outcome of maintaining the expectation that you will never be happy again?" Likewise, in learning, for instance, that the bereaved person's social network is steadily withdrawing from him or her, the therapist might encourage the individual to specifically set up a time to discuss this topic openly with family or friends and engage in corrective action.

Using exposure and cognitive restructuring techniques, therapists help clients face internal and external stimuli in order to learn that tolerating loss-related distress is possible and that ultimately it lessens suffering rather than increases it. Similarly, clinicians can employ behavioral activation to target depressive avoidance that may have prevented the survivor from engaging in pleasurable activities. Primarily, this is accomplished by encouraging the client to engage in gratifying activities even before he or she senses an intrinsic ability to do so. As Boelen, et al. (2006) aptly argued, "action often precedes mood improvement and adjustment" (p.111). A randomized, controlled trial of CBT for CG demonstrates that it outperforms supportive counseling, and suggests that exposure interventions may be especially effective (Boelen, de Keijser, van den Hout, & van den Bout, 2007).

**Meaning reconstruction approaches to grief therapy** (Neimeyer, 2000) posit that grieving entails an active effort to reaffirm or reconstruct a world of meaning that has been challenged by loss. In this perspective, people are viewed as meaning-makers, drawing on personal

and cultural resources to construct a system of beliefs that permit them to anticipate and respond to the essential events of their lives. The life-threatening illness and death of a loved one, however, can challenge this framework, sometimes calling into question the central themes of a person's worldview and self-narrative, or life story, across time. Such a perspective accords well with a growing body of research that points to the anguished search for meaning into which the bereaved are frequently cast, and the tendency for enhanced sense making in the wake of such tragic losses to be associated with more favorable bereavement outcomes (Neimeyer & Sands, 2011).

Accordingly, therapeutic efforts concentrate on two key domains of meaning reconstruction, through assisting the bereaved individual to process the *event story* of the death as well as to access and reconstruct attachment security in the *back story* of his or her relationship to the deceased (Neimeyer, 2011). For example, following careful cultivation of an empathic presence to the mourner's pain, the therapist can support him or her in retelling the narrative of the loss, with emphasis on those occurrences that were particularly distressing and likely to be "edited out" of the accounts shared with others. Tacking back and forth between the external, objective story of what transpired and associated internal feelings and emotions, the therapist is vigilant for unanswered questions and troubling meanings implied by the account, and joins the client in seeking more sustainable answers. Likewise, the therapist joins the client in the characteristic quest to not so much relinquish attachment to the deceased, as to reconstruct it in a form that does not require his or her physical presence in the client's life. For example, the therapist may use any number of experientially vivid techniques to invoke the presence of the deceased in therapy (e.g., through a review of photos or mementos, symbolically corresponding with the deceased or facilitating conversations between the deceased and the bereaved, with the latter loaning the former his or her voice to reanimate their dialogue).

A distinctive feature of this constructivist approach is the use of creative writing to promote both review of the event story of the death in a way that promotes sense making and benefit finding in the experience, and accessing the ongoing relationship with and legacy of the deceased as a source of security and continued orientation in living. Such techniques have found support in randomized, controlled studies of writing interventions that foster meaning making and perspective taking in the wake of loss, both in conventional written (Lichtenthal & Cruess, 2010) and internet-administered (Wagner, Knaevelsrud, & Maercker, 2006) form. A representative set of methods for promoting meaning reconstruction appears in Summary Table 3, and detailed instructions for several of these methods have been provided elsewhere (Neimeyer, 2012). Video demonstrations of meaning reconstruction in actual cases of grief therapy are also available (Neimeyer, 2004, 2008).

### **An Illustrative Case Study**

Kenya's pursuit of therapy (with the first author) was prompted by a number of recent but frightening physical symptoms, which included dizziness, rapid heartbeat, and racing pulse, accompanied by general sadness and spiritual malaise. When thorough medical testing disclosed no organic basis for these reactions, her physician referred her for psychotherapy with a diagnosis of "panic attacks of psychogenic origin" as well as possible depression, which had been unresponsive to medication. Presenting for her first session attractively attired in a conservative suit, Kenya noted that her symptoms worsened when she prepared to leave the northern city that had been "her only home" some five months earlier to follow her husband's "call" to take a position as the pastor of a southern African American church over a thousand miles away. Now, distant from her mother, sisters, and friends in the community that had shaped and sustained her, she found herself becoming increasingly reclusive, lest members of the new congregation discover her "emotional problems" and label her as

“crazy.” Over the past several weeks, Kenya confided, she had begun to “pull away” from her husband, George, and 12 year-old daughter, Leitha, deepening her concern that she not only was failing as the “first lady” of her church, but also was “losing herself” and those she loved.

After exploring Kenya’s understanding of her problem in more detail, I inquired about any previous experiences she might have had with therapy, and learned that she had briefly sought counseling following her father’s death a few years before, the stress of which had been compounded by the long illness that preceded it, and for which she and her mother had been the primary caregivers. Tears rolled down Kenya’s cheeks in response to my empathic inquiry about the trembling in her lip as she recounted her father’s passing, and she noted that she had only in the past year begun to cry for him, as his uncharacteristic “meanness” during his illness and treatment left her with a complex blend of avoidance and grief over his passing. Now, she realized, she keenly felt the separation from him, and, speaking quietly through a haze of tears, added that, “He would have been able to give me advice about moving, if only he were here.”

Alerted to the emotional vividness of this material for Kenya years after her father’s death, and struck by her spontaneous linkage of his absence with the problems in her relocation, I gently asked Kenya if she would like to invite her father to join us in the therapy room, to reopen a relationship with him that had been interrupted by his illness and death. Intrigued, she accepted the suggestion, and with guidance began a conversation with her father, who we symbolically offered an empty chair positioned across from his daughter. Sobbing, Kenya recounted to her father the outlines of her current problems, and, after a few seconds of silence, deepened her disclosure to include her feeling of guilt for having “abandoned” him by leaving the city in which he had lived for his whole adult life, to move to the South he had known only as a boy.

Accepting my suggestion that she take her father’s place and respond to what she had said,

Kenya changed chairs, dried her tears, and offered reassurance, concluding with, “Don’t worry, Baby, I’ll come visit you,” words that rung strangely hollow in view of the poignant sense of loss that Kenya had shared only moments before. Again taking her own seat at my gesture, Kenya repeated the words I tentatively offered to her: “You can’t visit me, Dad. You’re dead.” Kenya then poured forth both her grief and self-doubt, punctuated by wracking sobs. As she grew quiet, I again invited her into her father’s chair, where, unprompted, Kenya (as her father) provided loving and genuine reassurance, affirming that, despite his death, he would always be with her spiritually and emotionally, always believe in her. This interaction triggered a startling insight for Kenya. In her words, “I realize now that I *can* keep him, that he *can* be with me, and that I can even come to know him more through the South that he loved.” Buoyed up by the newfound reconnection with her father, Kenya then went on to consider her own sense of being uprooted from the surviving members of her family of origin, who, like her, were “struggling together to make sense of this new transition.” As our first session ended, Kenya somewhat sheepishly shared her wish to pursue advanced schooling, despite her “first lady” status. However, serving as a cultural interpreter, she described for my benefit as a Caucasian therapist the implicit social expectations within some African-American faith communities that constrained this potentially “selfish” goal. Eager to pursue the “fresh ideas” generated in the session, Kenya closed by requesting another appointment.

In her remaining three bi-weekly sessions, Kenya deepened her exploration of both her history of loss, revisiting the story of the death of an infant son early in her marriage, and renewed her effort to “find her own voice” as a woman in her family and church community. As she did so, she remarked with some surprise that life was starting to seem somehow “more real,” and she related with pride several concrete instances in which she had negotiated important family decisions with her husband, played a more active role in providing guidance to her pre-teen daughter, and “stood up”

for innovative programs she advocated in the church. In all of this, she continued to experience a strong sense of her father's presence and pride in her, and the feeling that something had "lifted" for her in the pivotal "conversation" with him in the opening session. In Kenya's own words, she no longer felt "held back," and was gratified by George's support for her being her own "outspoken" self, even to the point of wearing neat, yet more casual clothes to both church committee meetings and therapy sessions. Perhaps most remarkably, she had been entirely freed of the panic symptoms from the point of her "conversation" with her father onward, despite these symptoms never having been made the specific targets of therapeutic intervention. Our therapy concluded by reflecting on the "changed narrative" of Kenya's life, which re-established a meaningful sense of continuity with who she had been (as anchored in an ongoing relationship with her supportive father), while also permitting her to "re-author" aspects of her identity in critical living relationships. Follow-up indicated that these changes were consolidated over the months to come.

### **Coda**

Loss may be inevitable in human life, but the experience of intense, protracted grieving is not. In this chapter we have summarized the features and risk factors for complicated grief, both in the context of end-of-life care and in subsequent bereavement, and attempted to offer some principles for mitigating the suffering of survivors. When these efforts to assist family members whose loved ones are dying are supplemented with therapies for those whose grief seems unresponsive to the passage of time, there is reason to hope that the bereaved can find their way from mourning to meaning, so that their own lives are strengthened through a containing bond with their loved one (Klass, Silverman, & Nickman, 1996) rather than damaged by loss.

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**Summary Table 1. Diagnostic Features of Complicated Grief**

1. Duration of bereavement of at least 6 months
2. Marked and persistent separation distress, reflected in intense feelings of loneliness, yearning for, or preoccupation with the person who has died
3. At least 5 of the following 9 symptoms experienced nearly daily to a disabling degree:
  - Diminished sense of self (e.g., as if a part of oneself has died)
  - Difficulty accepting the loss on emotional as well as intellectual levels
  - Avoidance of reminders of the reality of the loss
  - Inability to trust others or to feel that others understand
  - Bitterness or anger over the death
  - Difficulty “moving on,” or embracing new friends and interests
  - Numbness or inability to feel
  - Sensing that life or the future is without purpose or meaning
  - Feeling stunned, dazed, or shocked by the death
4. Significant impairment in social, occupational, or family functioning

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Adapted from (Prigerson, et al., 2009) and (Shear, Simon, et al., 2011)

**Summary Table 2. Pre-loss Risk Factor Checklist for Complicated Grief**

Research suggests that the following characteristics of the individual or family, the death itself, and the treatment context are associated with poorer adjustment in bereavement.

*Background factors*

- ✓ Close kinship to the dying patient (especially spouse or child loss)
- ✓ Female gender (especially mothers)
- ✓ Minority ethnic status (in the United States)
- ✓ Insecure attachment style
- ✓ High pre-loss marital dependency

*Death-related factors*

- ✓ Bereavement overload (multiple losses in quick succession)
- ✓ Low acceptance of pending death
- ✓ Violent death (suicide, homicide, accident)
- ✓ Finding or viewing the loved one's body after violent death
- ✓ Death in the hospital (vs. home)
- ✓ Dissatisfaction with death notification

*Treatment-related factors*

- ✓ Aggressive medical intervention (e.g., ICU, ventilation, resuscitation)
- ✓ Ambivalence regarding treatment
- ✓ Family conflict regarding treatment
- ✓ Economic hardship created by treatment
- ✓ Caregiver burden

### Summary Table 3. Techniques for Facilitating Meaning Reconstruction in Bereavement

As bereavement typically challenges mourners to contend with the significance of the loss as well as to reconstruct their relationship to the deceased, meaning-centered therapy incorporates a variety of procedures for promoting both outcomes. The following representative sample of techniques is derived from the manual of creative practices for grief therapy compiled by Neimeyer (2012), which provides detailed instructions for each, illustrated by case studies.

<b>Processing and Integrating the Event Story of the Death</b>	
<i>Retelling the Narrative of the Death</i>	Slow-motion review of the loss story to promote mastery
<i>Loss Timelines</i>	Situating the current loss in the landscape of previous experience
<i>Virtual Dream Stories</i>	Creative writing about loss themes to facilitate their exploration
<i>Playing with Playlists</i>	Tracing the trajectory of love and loss in musical memoir on iPod
<i>Figurative Sand Tray Therapy</i>	Constructing symbolic stories using figurines in sand world
<i>Analogical Listening</i>	Focusing on bodily felt sense of grief and giving it expression
<i>The Body of Trust</i>	Depicting impact of the death story in mixed media on body image
<i>Directed Journaling</i>	Diary work to consolidate sense-making and benefit-finding
<i>Loss Characterization</i>	Narrating overall impact of loss on one's sense of self
<i>Overt Statements</i>	Voicing deep meanings that make chronic grief necessary
<i>Rituals of Transition</i>	Symbolically validating life changes occasioned by loss
<b>Accessing and Reconstructing the Back Story of the Relationship to the Deceased</b>	
<i>Introducing the Deceased</i>	Reclaiming the deceased as a participant in one's ongoing life
<i>Imaginal Conversations</i>	Visualizing the deceased while addressing unfinished business
<i>Correspondence with the Deceased</i>	Inviting an "exchange" of letters to renegotiate the relationship

<i>Chair Work</i>	Choreographing deeply authentic conversation with the deceased
<i>Life Imprint</i>	Tracing the impact of the deceased on one's values and decisions
<i>Reviewing the Photo Album</i>	Consolidating memories with the therapist as a witness
<i>Prescriptive Photomontage</i>	Constructing creative composite image of deceased's role in life
<i>Memory Books and Boxes</i>	Organizing mementos and messages that honor legacy of the lost
<i>Rituals of Connection</i>	Symbolically validating continuing bonds

**Clinical Pearl 1. Areas of Concern in Bereavement and Associated Principles of Intervention***Early responses to death*

- *Initial grief responses are most intense*, and call for immediate support, though not necessarily formal therapy.
- *Lack of warning regarding the death forecasts more severe bereavement distress*, which can be mitigated by keeping families fully and honestly informed regarding their loved one's changing condition.
- *Perception that the death was preventable predicts more intense grief*, suggesting a role for realistic assurance that the family and medical team did all that could reasonably be done to preserve the patient's life.

*Cognitive and behavioral factors*

- *Negative interpretations of the self, world, and future in the wake of loss are associated with more complicated grief*, and could be indications for professional therapy if self-criticism or fatalism becomes entrenched.
- *Avoidance of the reality of the loss impedes adaptation*, highlights the relevance of interventions that involve review of the narrative of the loss using compassionate witnessing and support, and requires collaboration in sorting through its implications for survivors.
- *An anguished search for meaning in the loss that finds no answers forecasts protracted grief*, and calls for spiritual or secular counsel to help survivors make sense of the death and find changed significance in their ongoing lives.
- *Low social support and negative, critical, or intrusive interactions exacerbate grief*, and call for provision of temporary support (e.g., in survivors groups) as well as possible therapy to promote skillful management of other relationships in the family or community.

## **Clinical Pearl 2. Principles of Family Therapy Near the End-of-Life**

End-of-life issues pose challenges for both families and clinicians engaged in the pre-loss therapeutic processes. In Family Focused Grief Therapy (FFGT; Kissane & Bloch, 2002), the process includes family members talking with each other about the illness and about their future needs, problems with engaging family members, limits to therapeutic goals, therapy in the home, cross-cultural challenges, working with families with young children, and ethical issues.

### *End-of-life discussions*

- *Talking about the illness and prognosis*, forthrightly, is easier for some family members if addressed speculatively rather than definitively, and if room is given to both those who maintain hope for positive progress and those who have already begun the grieving process.
- *Discussions about future needs*, once the loved one has died, are facilitated by future-oriented questions that identify anticipated needs and outline a proactive plan for engaging support.

### *Therapy challenges*

- *Engaging family members in conversation* is most difficult in families with minimal cohesion, requiring extra involvement on the part of the clinician.
- *Limits to therapy goals* exist in the face of the myriad pre-illness and ongoing stressors facing even the most intact families.
- *Home therapy* occurring alongside hospice care may not suit every family, and requires the establishment of boundaries in order to prevent barriers to therapy.
- *Cross-cultural issues* surrounding death rituals and end-of-life mores can cause unnecessary family stress unless addressed openly, with respect for differing views.
- *Young children* in a family anticipating a parent's death require special consideration to facilitate a healthy grieving process, which, in turn, can bolster the confidence and skills of

the surviving parent.

- *Maintaining an “ethic of care”* is the basis of FFGT, with preference and sensitivity shown to various family members in need of special attention at a given point in the dying and grieving process.