Abstract

There are several ways, clinically, to approach grief after perinatal death, including from a humanistic or a medicalized perspective. The death of a baby is complicated. The loss is an embodied one that incites deep psychological wounds and can be isolating for many parents. Parents process their grief experiences within a sometimes oppressive social context that either sees their expressions of loss as a normal response to an abnormal tragedy or as pathology. Several diagnostic categories have been proposed relative to the traumatic grief experiences of grieving parents that potentially affect them. We explore this nomenclature and, through the lens of a Social-Cognitive Processing Model, examine social support, attitudes, context, and oppressive interpersonal and social structures that affect parents. Clinical implications are discussed.
Key words: Bereavement; Grief; Perinatal death; Psychological trauma; Stillbirth.

Normal Complications and Abnormal Assumptions After PRENATAL DEATH

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Perinatal death often incites traumatic grief in parents, just as any child's death.

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There are several ways to approach grief after perinatal death, including a humanistic or a medicalized perspective. Death of a baby, or any aged child, is catastrophic for family systems. The highly dependent nature of the relationship, the unexpectedness of a child's death in modern times, and deep emotional and evolutionary attachments cause intense anguish for parents. Specifically, death of a baby is exceptional and differs from death of an older child. Perinatal death is an embodied loss, happening within a mother's body. Yet, the psychological wounds of losing a baby can be isolating for many parents who process their grief within a social context. Broader systems, including medical, faith, familial, and societal, affect grieving parents by viewing their traumatic grief as either a normal response to an abnormal tragedy or as pathological. Much like other forms of oppression, such as exposure to microaggression, prejudice, and discrimination, which result in psychological stressors for individuals and families (Utsey, Giesbrecht, Hook, & Stanard, 2008), interpersonal and structural determinants have a profound impact on vulnerable, grieving parents. These oppressive structures incite shame that "may also be internalized by the bereaved individual, who describes frustration at his or her inability to 'keep it together' or to 'move on and stop wallowing in self-pity'" (Harris, 2010, p. 246). The grieving individual sacrifices trust in his or her own emotions in an effort "to conform to the social grieving rules, even when adherence to these rules could prolong their personal suffering after a loss" (Harris, p. 246).

Grief, Traumatic Grief, and Perinatal Death

Bereavement is a unique life event that occurs in the context of individual circumstances. Variables, such as relationship to the deceased, high dependency and attachment, whether the death was expected or not, manner of death, spiritual beliefs, socioeconomic status (Cacciatore, Killian, & Harper, 2016), concordant partner responses, and perceived level of social support (Cacciatore, Schnebly, & Frøen, 2009) all affect a person's responses. Death of a child is a painful loss provoking intense and long-lasting grief that can last years and even decades (McCarthy et al., 2010; Rogers, Floyd, Seltzer, Greenberg, & Hong, 2008).

One of the features unique to stillbirth is that the death takes place inside the mother's body. During birth, changes occur in the woman's body to accommodate the baby's arrival. The endocrine system releases adrenal hormones and responds to pain receptors in the woman's body. Powerful contractions force cervical dilation. A surplus of neurotransmitters stimulates the production of breastmilk and intense maternal bonding behaviors. However, when the baby is born dead, those primal messages of birth, attachment, and love coalesce with messages of death and grief. It is a psychic impasse for mothers who have just endured the process of giving birth. Fathers are also deeply affected by the death of a baby but may be less willing to share their emotions about the loss or cry and may show lower grief intensity as measured by existing instruments that tend to focus on emotional experiences (Kersting & Wagner, 2012).

Giving birth to a dead baby is a psychobiological trauma: the parallel paradox of birth and death. It is an emotional, spiritual, and physiological experience, enveloped in heartbreaking grief and shame. Yet, for many mothers, and even fathers, this tragedy is often overlooked and minimized in research, policy, and societal attitudes that tend to minimize the value of the baby's life (Cacciatore & Bushfield, 2008). There is often a sense of helplessness, despair, and terror during the acute crisis when the process of birth will end in death, not life. The medical community has now taken steps to assert diagnoses relevant to the question: What is normal and what is pathological grieving?

Diagnosing, or Misdiagnosing, Traumatic Grief

Most scholars and clinicians agree that manifestations of grief can endure months, years, and sometimes decades. This is particularly true when losses are traumatic and untimely. Yet, current trends in psychiatry and related fields are toward restricting the timeframe in which grief expressions are considered normal. Examples are reflected in changes to the most recent version of the Diagnostic and Statistical Manual of Mental Disorders (*DSM-5*), widely used for diagnostic purposes and closely tied to third-party reimbursement for treatment. The first change is the removal of the caveat that a clinician should be wary of diagnosing Major Depressive Disorder (MDD) if symptoms occur within 2 months of bereavement and

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are not severe (American Psychiatric Association, 2013). Because the symptoms of grief and depression are virtually indistinguishable, this caveat, known as the bereavement exclusion, was meant to prevent an inappropriate diagnosis of MDD in grieving. As a result of this change, a clinician can now diagnose a griever with MDD only 2 weeks after a death, regardless of the context.

This decision generated considerable debate and outrage among mental healthcare professionals, scholars, and the public. Some contended that it would expand access to treatment and others voiced concern over the pathologization of normal grief and sadness, as studies showed the bereavement exclusion more precisely differentiated normal bereavement from pathology (Thieleman & Cacciatore, 2013). Its removal is likely to result in additional false-positive MDD diagnoses among the bereaved (Wakefield, Schmitz, & Baer, 2011), especially in groups where long-lasting grief is normative.

As a result of this change, increasing numbers of the bereaved may be classified as clinically depressed (Clesse, Leray, Bodeau-Livinec, Husky, & Kovess-Masfety, 2015). Bereaved mothers are at particular risk, as they report higher levels of distress and tend to be more emotionally expressive (Kersting & Wagner, 2012). Approximately twice as many women as men are already diagnosed with MDD (Van de Velde, Bracke, & Levecque, 2010), reflecting a wider trend of the *DSM* pathologizing emotional expression (Marecek & Gavey, 2013). Due to significant overlap between traumatic grief and MDD symptoms considered "severe," including fatigue, distress, and thoughts of death (Thieleman & Cacciatore, 2013), bereaved parents are likely to meet MDD criteria.

Along with the change to the MDD criteria, a proposal for new grief disorder was included in the *DSM-5* appendix as a condition for further study. Persistent Complex Bereavement Disorder (PCBD) includes symptoms such as yearning for the deceased, intense emotional pain, or preoccupation with the deceased or circumstances of death. Included in the diagnosis are symptoms of reactive distress or social/identity disruption that persist for more than a year (American Psychiatric Association, 2013). Notably, other proposals call for a duration criterion of only 6 months (Maciejewski, Maercker, Boelen, & Prigerson, 2016). Like other proposals for grief disorders, PCBD does not contain any symptoms not found in normal grief specific to certain populations, such as grieving parents. It assumes that persistence of grief past a certain point in time is pathological (Thieleman & Cacciatore, 2013; Wakefield, 2012). However, grief is known to commonly extend far beyond 1 year in some populations.

Common features of grief in bereaved parents may make misdiagnoses more likely. In a study of individuals who met criteria for complicated grief, bereaved parents had higher overall scores and symptoms of preoccupation, yearning, bitterness, anger, disbelief, shock, self-blame, and thoughts of death. Parents mourning children under 25 years of age expressed a greater wish to die than those mourning older children (Zetumer et al., 2015). In another study 18 months after a child's death in the South Korean Sewol ferry accident, 94% of parents met criteria for complicated grief, and 65% showed high levels of bitterness, likely in response to how the ship's operators and the government handled the disaster (Huh, Huh, Lee, & Chae, 2017).

Continuing bonds between parents and their deceased children are widely seen as a continuation of parent–child attachment. However, there is significant overlap between symptoms of PCBD and experiences of bereaved parents seeking to maintain these bonds. In one study, bereaved parents thought often about their child and kept their special belongings. They also engaged in more activities to honor and remember the child, deriving comfort from these experiences (Foster et al., 2011). These attachment-oriented experiences may be considered symptoms of yearning and preoccupation under criteria for PCBD.

There is little doubt that proposals for pathological grief disorders, rarely tested with bereaved parents, disproportionately capture normal experiences within this group. Although the prevalence of PCBD was estimated to be 14% (Maciejewski et al., 2016), in studies on Prolonged Grief Disorder (PGD), essentially the same construct as PCBD (Maciejewski et al.), demonstrate that the percentage of bereaved parents meeting criteria is quite high, with population-based studies reporting 24% (Kersting, Brähler, Glaesmer, & Wagner, 2011), 48% to 78% (Dyregrov, Nordanger, & Dyregrov, 2003), and 81% to 96% (Xu, Herrman, Bentley, Tsutsumi, & Fisher, 2014) at various time points after the loss.

The focus on identifying pathological grief, with 6

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months or 1 year as the duration criterion, may be shifting societal understanding of normality in traumatic grief. In one study of complicated grief in the homicidally bereaved, the authors wrote, "Questionnaires were sent minimally six months post loss, to allow time for normal grief" (van Denderen, de Keijser, Huisman, & Boelen, 2016, p. 211). Unsurprisingly, *82% of the sample met criteria for complicated grief*, and bereaved parents and spouses were at greatest risk. The "lack of reliable and valid diagnostic criteria to accurately differentiate" what others deem as "normal" grief from what is deemed abnormal grief poses an "obstacle for health care providers" (Hutti et al., 2018, p. 128) that may adversely affect patients.

Being diagnosed with a grief disorder may evoke stigmatization, the ascribing of negative cognitions about grief, and the desire for greater social distance in others (Eisma, 2018). Instead of considering context, the *DSM* relies on arbitrary time limits that obfuscate the line between normal responses when applied to one of the most abnormal events a family can experience—the death of a child during the perinatal period.

Treatment as Usual and Do No Harm

Frequently the first, and often only, intervention offered for mental disorders is psychotropic medication (Mojtabai & Olfson, 2008). Despite this, the efficacy of such medications in traumatic grief has not been empirically supported (Thieleman & Cacciatore, 2013). A substantial body of research suggests that this approach is not as safe or effectual as once believed (Lembke, Papac, & Humphreys, 2018). Although there exists a dearth of sound empirical data supporting medications for treating grief, there seems to be an increase in prescribing to parents shortly after a child's death. This even occurs prior to the duration criterion for a mental disorder has been met (Lacasse & Cacciatore, 2014). Within the first 8 weeks of a baby's death, intense grief was five times more likely to predict the use of pharmacologic intervention than nonintense grief (Hutti et al., 2018). This is particularly concerning because many women who experience perinatal death will go on to have subsequent children. Some research suggests that selective serotonin reuptake inhibitors, commonly used to treat depression, pose developmental and physical risks to babies during pregnancy (Boukhris, Sheehy, Mottron, & Bérard, 2016; Tuccori et al., 2010).

Grieving in a Social Context: Poor Adjustment and Victim Blaming

The Social-Cognitive Processing Model can be used to understand adjustment in bereavement by considering social support, attitudes, context (Belsher, Bongar, Ruzek, & Cordova, 2012), and oppressive interpersonal and social structures. Grievers who are surrounded by compassionate others tend toward being more self-compassionate toward their grief, more willing to approach their emotional distress than avoiding it. This can increase their sense of control, self-efficacy, and revivification processes. Research has shown that social constraints, that is suppression of loss-related emotional material by others, "may be a common risk factor for maladjustment during bereavement" and are associated with higher levels of maladjustment, stress and somatic symptoms, and poorer global health (Juth, Smyth, Carey, & Lepore, 2015, p. 145).

Waning social support and critical social edicts around grief challenge an individual's sense of self-efficacy and autonomy (Benight & Bandura, 2004). This can result in compromised trust in one's own emotional experiences associated with loss. Instead of accepting grief-related emotions as normative and healthy, pervasive self-doubt incites questioning and rumination and, when unresolvable, avoidance. Intense grief after a baby's death is often exacerbated by incongruence between what grieving parents feel about their grief and what others think they should feel. The inability to "confront others to resolve issues that arise during the course of the loss" (Hutti et al., 2018, p. 128) can incite psychological harm.

Self-efficacy is a centrally important protective factor when traumatic events occur. It uniformly predicted fewer avoidant behaviors and aversive ruminations in widows, leading to less emotional distress and better physical health outcomes (Benight & Bandura, 2004). Boelen, Reijntjes, Djelantik, and Smid (2016) found that "catastrophic misinterpretations of grief" (p. 362) was the only variable distinguishing those who met criteria for PGD from those determined to be resilient. In cases of "unnatural losses"—and few deaths are as unnatural as the death of a baby—yearning as a symptom was a common response and not indicative of pathology (Boelen & Hoijtink, 2009). Rather, it can be reasonably viewed as evidence of a normal response to an abnormal tragedy under tremendous social pressure to "recover" from grief.

Clinical Implications

Death of a baby is an unresolvable biopsychosocial contradiction for parents and families. What should be a zenith day filled with joy is traumatizing and excruciating. Parents are too-often then met by insufficient social and medical systems that fail to comprehend acute and long-term dimensions of traumatic grief. Those grieving "frequently report distress over not just the loss(es) they have experienced, but also to their responses to these losses" (Harris, 2010, p. 242). Adverse psychological outcomes are often exacerbated by friends, family members, others in their social systems, and even healthcare providers (Harris; Hutti et al., 2018). Gender differences in coping and discordant grieving styles may lead to relationship difficulties between parents (Kersting & Wagner, 2012). This issue may need to be addressed by those caring for grieving parents.

Parents who experience a baby's death need and deserve sensitive support from their providers and communities. Their grief may be protracted, with persistent yearning and enduring distress. However, for this specific population, such symptoms appear normative and can be understood as such from an evolutionary attachment perspective.

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FIGURE 1. Dysregulated Coping Path

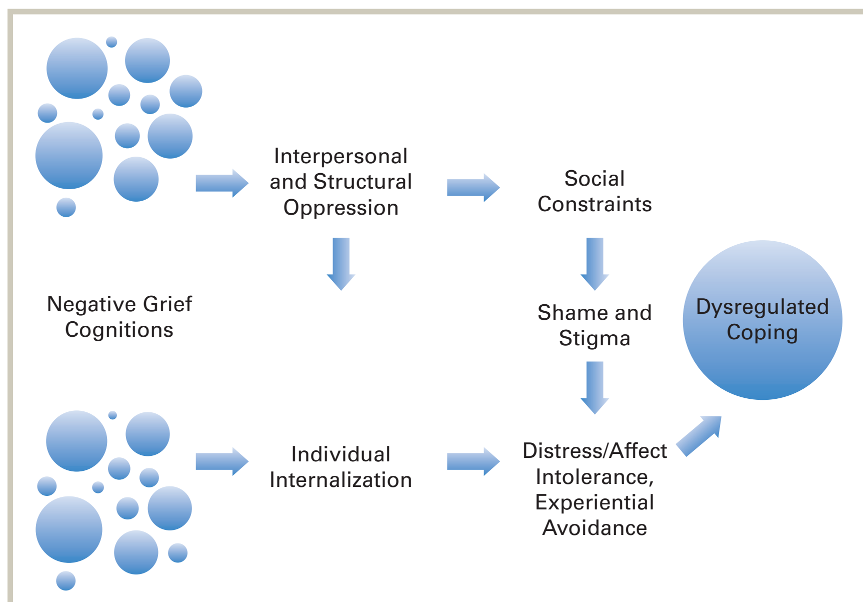
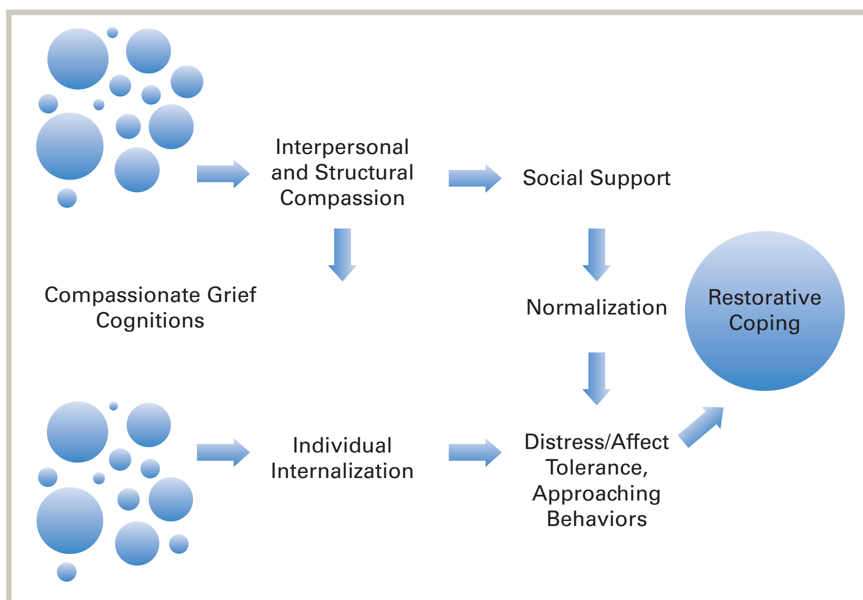


FIGURE 2. Restorative Coping Path



Based on epistemological evidence, negative individual cognitions about one's own grief, often influenced by social edicts, constraints, oppression, and the general lack of support in a grief-avoidant culture, can have deleterious effects on coping and psychological adjustment. As noted by Harris (2010), grieving people "counteract the potential for social isolation or exclusion from lack of conformity to expectations," through forced stoicism, "internalizing the oppressive forces that are enforced through the social rules of acceptability after a loss occurs… and so grief goes underground" (p. 247). Interpersonal and structural oppression, combined with negative cognitions about grief, are often internalized by grievers, leading to shame, stigma, affect intolerance, and experiential avoidance. Ultimately, this process may be the source of exacerbation for what appears to be pathological bereavement. Figure 1 depicts how negative grief cognitions after the death of a baby, influenced by interpersonal and structural oppression, can lead to internalization of these cognitions. This, in turn, reinforces social constraints and isolation, leading to shame, stigma, distress and affect intolerance, as well as experiential avoidance. Ultimately, these processes increase potential risk in dysregulated coping.

Conversely, Figure 2 depicts how interpersonal and structural compassion can influence parents' self-compassion toward their suffering. Compassion from interpersonal and structural sources leads to enhanced social support and the normalization of grief responses, helping parents internalize more realistic expectations and acceptance of their grief and other related emotions. This leads to increased distress and affect tolerance and promotes approaching, rather than avoiding, behaviors toward grief. The result is more adaptive, restorative coping and better long-term psychological adaptation for parents after the death of a child, despite the persistence of grief. In this model, grieving parents are better poised to cultivate a relationship with their grief that fosters growth and meaning, if and when they are ready.

The death of a baby is a complicated contradiction but the assumption that parental grief is abnormal, a medical disorder to be treated, is itself a social pathology. Parents grieving the death of a baby aren't abnormal. Rather, interpersonal and structural oppression around their grief are the abnormity. That death and birth meet together in a long-awaited, intimate moment of the human experience is a perilous psychic wound. Many, if not most, bereaved parents experience long-term psychological distress on a variety of measures and are eligible for a diagnosis under the current taxonomic system. Yet, if the preponderance of grieving parents consistently report high levels of distress, and thus qualify for a *DSM* or ICD bereavement-related diagnosis, would not their subjective experiences actually represent a *normal* reaction to this type of *abnor-*

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Suggested Clinical Implications

- Intervention models should focus on both acute and long-term care to help support families through traumatic deaths, with attention to the possibility that mothers and fathers will use different coping strategies.
- Allow families to spend private time with their baby who died and encourage them to hold their baby, if desired. If family members express fear around seeing or holding the baby initially, provide psychoeducation about any concerns and offer other opportunities for ritual, while leaving open the possibility of seeing or holding the baby in the future.
- Do not rush parents. Rather than pressuring them to make arrangements for final disposition or sending them home from the hospital quickly, give them as much time as possible to absorb the initial trauma of their loss.
- Facilitate culturally sensitive rituals such as washing and dressing the baby, taking photographs, and helping create other memories and mementos of the parents' choosing.
- Embody patience, humility, and compassion (Hutti, 2005); share information with other staff members who are providing care to ensure sensitive treatment of grieving parents by all caregivers.
- Provide care that includes counseling and psychoeducation to parents, siblings, and grandparents around what is normal in traumatic grief. Validating grief, preparing for holidays, compassionately discussing partner intimacy questions, and providing follow-up support (Hutti, 2005) are of the utmost import. Hutti notes the importance of helping parents to confront others' reactions to, and perhaps judgments about, their grief; in this way, "instead of feeling victimized, the parent feels empowered" (p. 635). This may have a profound impact on grieving parents' self-trust and self-compassion.
- Engage a wait-and-watch policy and do not hasten psychiatric diagnoses or the prescription of psychiatric medication.
- Provide access to professionals specifically trained in traumatic grief, from hospital care and funeral staff to therapists and physicians, without requiring the assignment of a mental disorder to accommodate insurance reimbursement. Current taxonomic structures in mental health fail to recognize that there are legitimate forms of suffering not caused by disorders. These intense grief reactions to the death of a baby are most often normal responses to an abnormally painful tragedy, one that is rife with delegitimization and stigma.

mal loss? Diagnostic criteria specifying that grief and sadness after the death of a child will resolve within 1 year, not to mention 2 weeks, represent unreasonable expectations that minimize attachment bonds between parents and their children and challenge what it means to love. These considerations should be kept in mind by nurses working with families during and after the death of a baby. Nurses are often poised to offer immediate support and their words and actions toward grieving parents in the midst of tragedy may influence long-term adjustment. ✣

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The authors declare no conflicts of interest.

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DOI:10.1097/NMC.0000000000000486

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