Parental Bereavement and Grief

Description/Etiology

Bereavement is a condition of losing someone close. Each year, millions of parents worldwide suffer the death of a child. Whether the death is sudden or anticipated or losing a fetus or a child of any age, losing a child undermines the natural order of life, and the grief for parents typically is profound, prolonged, and life-altering. Grief, defined as the individual’s reaction to major loss characterized by a period of sorrow, emotional numbness, and, in some cases, guilt and anger, is a healthy, normal response to losing a loved one that usually fades as the affected person accepts the loss. Grief is deeply personal, and each response is unique. Its intensity can disrupt a parent’s identity, as well as adversely impacting both individual and family function. Despite profound sadness and distress, many bereaved parents also report transformative impacts following the loss of a child, including changed priorities, heightened compassion and spirituality, and a greater appreciation of life and relationships.

The experiences of parents differ in part based on the circumstances of the child’s death, including whether the death was the result of miscarriage, stillbirth, illness, accident, violence, or suicide. A substantial number of bereaved parents have experienced perinatal loss (e.g., miscarriage, stillbirth or neonatal death) and feel significant distress, including isolation, depression, and increased anxiety and hypervigilance with other children and subsequent pregnancies. They can also experience disenfranchised grief (i.e., a loss that is not socially recognized and supported) (Burden et al., 2016). Parents also differ in their well-being and functioning before experiencing the death of a child. Parents whose children died as a result of suicide have been found to have higher rates of depression, anxiety, alcohol abuse/dependence, health problems, and low income before the child’s death than parents whose child died as a result of a motor vehicle accident (Bolton et al., 2013). Gender, cultural and spiritual factors, previous losses, and the presence of additional stressors can also influence grief responses and adjustment.

For most individuals, the acute grief transforms over time into integrated grief (i.e., they can integrate the reality and emotional pain of their loss and move forward with their lives); for some, the grief state persists to the point of debilitation. In persons with complicated grief (also called prolonged, traumatic, and pathological grief), painful emotions, including nonacceptance of the loved one’s death, are so long-lasting and severe that individuals are unable to resume their normal daily activities. The Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5), added proposed criteria for “persistent complex bereavement disorder” in the chapter on conditions for further study. The proposed criteria include the death of someone close; the presence for at least 12 months of clinically significant distress or functional impairment; persistent longing for the deceased, preoccupation with the deceased or the manner of death, or intense emotional distress; and six symptoms specific to reactive distress to the death or related social and identity disruption (American Psychiatric Association, 2013). Parents who develop complicated grief are at increased risk for comorbid mental health conditions and suicide. More mothers suffer complicated grief symptoms than fathers, which is thought to be related to the strength of the maternal attachment bond. Where there is limited partner closeness or no partner, there is an increased risk of mental and physical health complications. Bereaved parents have higher rates of physical illnesses, including cancer and multiple sclerosis, and increased mortality. Symptoms of complicated grief that persist for at least 6 months are...
associated with mental health problems and poor bereavement outcomes (e.g., divorce, neglect of other children).

The healing process for bereaved parents involves learning to adapt to and reinvest in life after the loss. Making sense of the loved one’s death is an important part of adapting to loss. The most common belief expressed by bereaved parents is that their child’s death was “God’s will”; many take comfort in thoughts of an afterlife or knowing that their child’s suffering has ended. Parents who lose a child to violence are more likely to have difficulty making sense of the loss of their child than parents whose child died of non-violent means (Lichtenthal et al., 2013). Bereaved parents often maintain a sense of connection with their deceased child. Internalized continuing bonds (i.e., abstract representation of the deceased) do not impede engagement in daily life and can be positive, but externalized continuing bonds (e.g., remaining preoccupied with mementos, visits to burial site) can be an indicator of difficulties with integrating the loss. Grief tends to be cyclical and triggered by events such as the child’s birthday, the anniversary of the death, and family milestones (e.g., weddings) that serve as reminders of the loss of future hopes for the child.

Support and treatment available to bereaved parents vary in part depending on the circumstances of the child’s death and may include services through health care providers and perinatal hospice programs, peer support groups, and/or psychotherapy. In several clinical trials, complicated grief treatment has been shown to be an effective treatment (Shear et al., 2016).

**Facts and Figures**

An estimated 6.6 million children died in 2017, of which 5.6 million were under the age of 5 and 1 million were between 5—14 years old (United Nations Children’s Fund, 2017). There are also an estimated 2.6 million stillbirths each year (Lawn et al., 2016). In the United States, 43,017 children and adolescents died in 2015; of these children, 23,455 died within the first year of life (Murphy et al., 2017). Complications resulting from preterm birth, neonatal sepsis, injury, and congenital abnormalities are among the leading causes of neonatal death worldwide (Liu et al., 2015). The most common cause of death in children and adolescents is an injury, although, homicide and suicide are also significant causes of death in adolescents (Wender & Committee on Psychosocial Aspects of Child and Family Health, 2012). There are no data on the number of adults who die while their parents are still living.

Researchers in a United States study found that 13 months after the hospital death of their child, 35% of mothers had clinical depression and 35% had post-traumatic stress disorder (PTSD); 24% of fathers had clinical depression, and 30% had PTSD; Hispanic and Black mothers were more likely to have PTSD and depression 6 months after the loss than White mothers (Youngblut et al., 2013). In another study, investigators reported that during the first 13 months after the hospital death of a child, mothers experienced more intense panic, disorganization, and despair than fathers but also experienced a lessening of grief intensity over time, whereas fathers’ grief did not decrease over the 13 months. Grief intensity did not differ significantly between mothers of different races (Youngblut et al., 2017). Investigators in the United Kingdom found that the coping strategies of bereaved parents had more influence on bereavement outcomes than the circumstances of the child’s death (Harper et al., 2014). In a United States study, bereaved parents with complicated grief, particularly those whose children were younger (under age 25) reported more severe symptoms, self-blame, and suicidal ideation than other individuals with complicated grief (Zetumer et al., 2015).

Researchers in the United States found that spiritual activities (e.g., self-reflection, meditation, reading inspirational literature, confiding in family or friends) were associated with decreased grief and depression in both mothers and fathers and decreased PTSD in mothers, whereas religious activities (e.g., prayer, attending church) did not have a significant impact on mental health outcomes (Hawthorne et al., 2016). Finnish mothers who participated in a grief support group did not experience less grief but did experience less panic, detachment, and disorganization (Raitio et al., 2015). In a randomized controlled trial in China, investigators tested the effectiveness of a family support program for women who experienced loss resulting from stillbirth or a pregnancy termination due to fetal abnormality: the participants showed significant improvement in depressive and post-traumatic stress symptoms compared with non-participants (Sun et al., 2017).

**Risk Factors**

Bereavement is a risk factor for major depressive disorder, anxiety disorders, and complicated grief. Parents who have preexisting depression or other mental health difficulties are at increased risk for complicated grief (Wender & Committee on Psychosocial Aspects of Child and Family Health, 2012). Women are at higher risk than men for complicated grief. Delayed or inhibited grief may also increase the risk for complicated grief. If parents decide not to have formalized or culturally appropriate rituals to mark the death of the child, there may be an increased risk of complicated grief.
**Signs and Symptoms/Clinical Presentation**

Acute grief typically includes intense sadness, longing, disbelief, protest, denial, preoccupation with thoughts and memories of the deceased, reliving the events surrounding the child’s death, a sense of a void in one’s life, and/or emotional numbness. Anxiety, anger, guilt, and/or remorse may be present. Physical symptoms of grief may include difficulty eating, long-term sleep problems, and fatigue. Cognitive deficits in concentration and memory processes also are frequent. Parents grieving for a child lost to suicide or a traumatic event report post-traumatic stress responses such as flashbacks, intrusive memories, excessive rumination, and extreme guilt.

Complicated grief symptoms are prolonged and include intense yearnings for the child, a sense of disbelief, numbness, anger, avoidance of reminders of the deceased, and intrusive thoughts and preoccupations.

**Social Work Assessment**

› **Client History**
  - Complete a thorough biopsychosocial-spiritual assessment, including assessing grief responses and the extent of social support
  - Screen for alcohol/substance use, comorbid mental health issues, and complicated grief and other bereavement complications
  - Assess parents for suicidal ideation/plan

› **Relevant Diagnostic Assessments and Screening Tools**
  - The Complicated Grief Assessment has 10 questions that help diagnose complicated grief symptoms
  - The Perinatal Bereavement Grief Scale short version has 33 questions, helps distinguish bereavement from depression, and is available in English and Spanish
  - The Scale for Suicidal Ideation (SSI) measures the intensity, pervasiveness, and characteristics of suicidal ideation

› **Laboratory and Diagnostic Tests of Interest to the Social Worker**
  - No laboratory tests are applicable

**Social Work Treatment Summary**

Support from family and friends as well as professionals is critical for parents experiencing acute grief (Meisenhelder & Gibson, 2015). Social workers can facilitate healthy mourning by providing a supportive environment and encouragement for parents to mourn, monitoring for and managing complicated grief, and referring for additional services as needed for co-occurring physical or mental health conditions (Shear, 2012). Emotional support for those who are grieving involves actively listening, acknowledging their loss and feelings, and validating that their emotions are normal and expected. Referring to the child by name and affirming the parent’s positive efforts also are appreciated by bereaved parents (Meisenhelder & Gibson, 2015). Support should be offered repeatedly, checking in at intervals for at least 6–12 months or longer following the child’s death (Gijzen et al., 2016).

Surveys of parents in the hospital setting indicate that the responses of the medical team can have significant positive and negative impacts; in general, parents appreciate when staff provided clear information and explanations, spent time with them, offered condolences, and provided emotional support (Ellis et al., 2016). In the period surrounding the child’s death, parents face an array of unfamiliar decisions and demands and need the support and guidance of professionals to navigate these challenges (Shelkowitz et al., 2015). Parents in intensive care settings often establish partnerships with healthcare providers over the course of the child’s treatment. Although the relationships change with the death of the child, they remain important as the parents continue to seek support and guidance from the providers (e.g., with intimate details such as caring for the child’s body, packing the child’s belongings, and saying farewell) (Butler et al., 2018).

Support for parents with a stillborn child can include having a special room in the hospital segregated from other newborns and parents and facility-sponsored memorial services (Gijzen et al., 2016). It is generally considered best practice to offer parents the opportunity to see and hold their stillborn baby (Koopmans et al., 2013), but parents may have reservations (e.g., fear regarding the child’s appearance) that can be allayed by information and support, thereby preventing regrets (Shelkowitz et al., 2015). Parents may also need assistance with arrangements that allow time to bond and experience parenting as well as obtaining memorabilia (e.g., a lock of hair or hand/footprints). Bereavement photography (i.e., having a professional photographer take pictures of the child before or after the child dies) may also be an option. Initial evaluations of bereavement photography suggest that it may contribute to the psychological wellness of a bereaved family (Blood & Cacciatore, 2014; Michelson et al., 2013). In addition to needing support regarding immediate decisions, newly bereaved parents may need assistance with identifying appropriate people in their lives who can provide ongoing assistance with practical tasks and/or surviving children (Meisenhelder & Gibson, 2015).
Bereaved parents can also find it helpful to connect with other parents who have had similar experiences (Gijzen et al., 2016). Mutual aid or support groups are beneficial, allowing parents to share their experiences, which in turn reduces feelings of isolation (Beggs et al., 2018). The Family Bereavement Program (FBP) is designed to promote resilience in parents who have lost a child. FBP consists of 12 two-hour group sessions led by counselors or social workers, each of which involves the teaching of a particular skill (e.g., positive coping, good communication, problem-solving), practicing the skill (role play), and assigning activities for practice at home. Evaluation of FBP has shown positive effects (e.g., better management of parent depression and grief, positive parent and surviving child relationship) at both 11-month and 6-year follow-ups (Ayers et al., 2013; Sandler et al., 2013).

An emerging intervention and resource for bereaved parents are peer support programs. Peer supporters are volunteers who have also lost a child and trained in bereavement support. Peer supporters follow up with bereaved parents on the phone and through home visits, as well as invite them to bereavement support groups (Aho et al., 2013). Parents have expressed that talking with someone who has experienced a similar loss can help normalize their feelings, but some were not ready to talk when initially contacted. Although flexibility is needed based on parents’ contact preferences, relationship-building is enhanced by face-to-face contact (Diamond & Roose, 2016). Although more research is needed, initial feedback and evaluations indicate that bereaved parents appreciate and value peer supporters (Aho et al., 2013).

A close marriage/partnership between the parents is an important coping resource in the short and long-term following the death of a child. Differences in the parents’ grieving styles can give rise to tensions in their relationship, although loss can also draw couples closer together. Counseling may be needed to strengthen the parents’ relationship or to help them work through challenges. For bereaved parents with a surviving child or children, a social worker can engage in therapeutic work with the parents to help them process and cope with their loss as well as maintain the ability to stay engaged, in tune with, and attached to their surviving children and re-establish a healthy family life. Part of this therapeutic approach will involve giving parents age-appropriate tools to help their children understand the loss of a sibling, the grief that often accompanies that loss, and ways to maintain a bond with the deceased sibling (e.g., writing letters to sibling, drawing family pictures to include sibling) (Bugge et al., 2014).

Psychotherapy can be beneficial in treating complicated grief, particularly cognitive behavioral grief-specific therapies such as complicated grief treatment (CGT) or cognitive behavioral therapy (CBT). Psychotherapy can include a variety of objectives, including psychoeducation about grief, processing the loss, restoring meaningful goals and social connections, and cognitive restructuring to deal with disruptive thoughts (e.g., self-blame). Although medications often are discouraged for grief because of the risk of overuse and because they can inhibit the expression of grief, some clients may benefit from short-term medication use and should consult their physician (Fortinash, 2012). Antidepressant medication in conjunction with complicated grief therapy can enhance improvement of depressive symptoms in individuals with complicated grief (Shear et al., 2016).

Social workers should be aware of their own cultural values, beliefs, and biases and develop specialized knowledge about the histories, traditions, and values of their clients. Social workers should adopt treatment methodologies that reflect their knowledge of the cultural diversity of the communities in which they practice.

Internationally, social workers should practice with awareness of and adherence to the social work principles of respect for human rights and human dignity, social justice, and professional conduct as described in the International Federation of Social Workers (IFSW) Statement of Ethical Principles, as well as the national code of ethics that applies in the country in which they practice. For example, in the United States, social workers should adhere to the NASW Code of Ethics core values of service, social justice, dignity and worth of the person, importance of human relationships, integrity, and competence. Become knowledgeable of and practice the NASW ethical standards as they apply to parental bereavement and grief (NASW, 2015).

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<tr>
<th>Problem</th>
<th>Goal</th>
<th>Intervention</th>
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<tr>
<td>A parent who has lost a child is experiencing grief</td>
<td>Healthy expression of grief</td>
<td>Help the client express and understand his or her grief. Suggest support groups, individual therapy, couples counseling, and family therapy. Encourage the client to increase social support network</td>
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<td>A parent has lost a child and is experiencing complicated grief</td>
<td>Adjustment to loss of child and recovery from complicated grief</td>
<td>Cognitive treatment revisits the loss with the client and has the client reimagine an ongoing relationship with the child and re-envision a future life without the child. Also, support groups, individual therapy, couples counseling, and family therapy should be considered. Encourage the client to increase social support network. Interventions for comorbid disorders may need to be prioritized</td>
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<tr>
<td>A parent who has lost a child is experiencing suicidal ideation</td>
<td>Elimination of suicidal ideation</td>
<td>Assess the client for suicide using a standard screening tool such as SSI. Determine if the client has a plan and means (e.g., gun, pills) to accomplish his or her suicide. Clients who have suicidal ideation without a plan should see a mental health professional as soon as possible. If there is active suicidal ideation and a plan, the client should be taken to an emergency room for assessment or whatever is the required action as per the agency protocol. If the client refuses to go, the police can be called for involuntary detainment</td>
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**Applicable Laws and Regulations**

› Social workers are bound by the “duty to warn” and must inform the proper authorities if the client is found to be a danger to him/herself or others. Social workers should be aware of the standards, procedures, and laws of the jurisdiction (e.g., nation, state, province) in which they work.

› Each country has its own standards for cultural competence and diversity in social work practice. Social workers must be aware of and practice the standards of practice set forth by their governing body (e.g., National Association of Social Workers [NASW] in the United States, British Association of Social Workers in England)

**Available Services and Resources**

› Bereaved Parents of the USA, [https://www.bereavedparentsusa.org/](https://www.bereavedparentsusa.org/)

› The Compassionate Friends, [https://www.compassionatefriends.org/](https://www.compassionatefriends.org/)


Food for Thought

There is no consensus on what constitutes an unhealthy or complicated response when a parent loses a child

The expression of bereavement differs across cultural and ethnic groups

Although most cultures have social and/or religious customs that provide support to families in times of loss, there are no established rituals that recognize the perinatal loss, which can be a very isolating experience. Social workers should be mindful that lack of social validation can contribute to parents becoming “trapped” in grief, and that they may need assistance in creating mourning rituals (Markin & Zilcha-Mano, 2018)

In some cultures, bereaved mothers are dissuaded from mourning stillbirths and infant deaths, in part due to beliefs about the potential impact of doing so on fertility. In a study in Ghana, investigators found that mothers continued to experience distress and grief regarding the loss of an infant, and would have preferred more communication with medical staff at the time of the child’s death (Meyer et al., 2018)

Patterns of lifelong grieving and feelings of acute loss can serve to maintain the emotional connection between the parent and the deceased child. Many bereaved parents welcome these emotions as a way to preserve the memory and value of their child

Marital/relationship closeness can help some parents through their grieving process and with adjustment; however, many parents divorce following the death of a child. Bereaved parents have a greater risk for divorce than nonbereaved parents. Knowing this, social workers should offer to provide marriage and family counseling beyond the crisis stage following the child’s death

Unlike an orphan, a widower, or a widow, there is no name for a parent who has lost a child

Many parents who lose children to suicide will deny that their child took his or her own life

Motherhood itself can be a protective factor for bereaved mothers if they have other living children. Their other children can provide a distraction from grief and can give them a sense of purpose and meaning in their day-to-day life

Researchers have linked bereavement with health problems and increased mortality of subsequent children. In a large study of children born in Denmark and Sweden to mothers who experienced the death of a child or spouse during their pregnancy or in the year before becoming pregnant, investigators found that by age 37, these individuals had a 3–18% higher mortality rate (Yu et al., 2017)

Red Flags

Clients with complicated grief are at higher risk for comorbid mental health conditions and suicide

Losing a family member in traumatic circumstances (e.g., suicide, homicide) has been linked with significantly increased rates of suicide ideation in surviving family members – in one study, 42% of family members reported suicidal ideation following a traumatic death (Williams et al., 2018)

Support groups for grieving parents work better when offered in the parents’ first language

When a child is terminally ill, support services should be offered before the child’s death, including individual and group counseling

Discharge Planning

Families who lose children require ongoing emotional support to assist them in adjustment to their bereavement

Provide psychoeducation regarding the normal grief process and signs of complicated grief

Refer bereaved parents to peer programs and/or support groups

DSM -5 Codes

296.xx, Major Depressive Disorder

309.81, Posttraumatic Stress Disorder

References


