



# Grief in the Context of Pediatric Oncology: Affective Bonds and Self-Care

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## ABSTRACT

Grief in the context of pediatric oncology represents one of the most painful and transformative experiences faced by parents and caregivers. This review article examines the specific characteristics of parental grief in response to a child's illness and potential loss, as well as the role of self-care throughout this process. An exploratory review of scientific literature published over the past twenty years was conducted using databases such as SciELO, Redalyc, and Google Scholar, prioritizing qualitative studies and systematic reviews. Findings indicate that although grief is a natural and adaptive process, it may evolve into emotional complications when symbolic elaboration is hindered. Particular attention is given to anticipatory grief, existential crisis, and the need for ethical and culturally sensitive psychosocial support. Finally, clinical recommendations are proposed to strengthen affective bonds and promote caregiver self-care within pediatric psycho-oncology settings.

**KEYWORDS:** Grief, Pediatric oncology, Caregivers, Self-care, Psycho-oncology

## OBJECTIVE

### General Objective

- To define the concept of grief and its specific characteristics within the context of pediatric oncology from the perspective of parents and/or caregivers.

### Specific Objectives

- To analyze the emotional and behavioral manifestations of grief among parents or caregivers of children diagnosed with cancer.
- To highlight the importance of self-care during the grieving process.
- To propose coping strategies for parents of children with an oncological diagnosis.

## INTRODUCTION

In the Spanish language, the term *duelo* has two distinct meanings. The first, associated with confrontation, refers to a “combat or fight between two individuals as a result of a challenge or dispute.”<sup>1</sup> This imagery of combat has historically been used as a metaphor to describe the experience of cancer, where patients and their families become engaged in a continuous struggle against the disease. The second meaning, more closely related to mental health and psycho-oncology, defines *duelo* as “pain, sorrow, affliction, or grief experienced due to someone’s death.”<sup>1</sup> This deeply emotional interpretation allows for a broader understanding of loss within the oncological context—not only death itself, but also the loss of health, life projects, bodily integrity, and the everyday life that preceded the illness. In this sense, grief acquires significant symbolic and clinical value, enabling a multidimensional understanding of cancer’s impact on the child and their environment.

The way grief is understood varies according to cultural meanings attributed to death. In Western culture, particularly under Christian influence, death is often conceived as a transition to another form of existence.<sup>2</sup> In some Indigenous cultures, death is not perceived as an end but as a reconnection with ancestors—a return to spiritual lineage.<sup>3</sup> According to Tibetan tradition, death represents not a final state but a transition through the intermediate state, or *bardo*, where the soul may attain liberation or prepare for a new existence.<sup>4</sup> These diverse perspectives enrich the understanding of grief as a universal process shaped by beliefs, rituals, and cultural frameworks.

Although the concept of grief is widely used in everyday language, it lacks a singular, universally accepted definition. Grief extends beyond a lexical description; it is an intimate and complex experience that cannot be reduced to a single statement.

From a psychological standpoint, grief is understood as a natural response to the loss of an emotionally significant figure. It is considered a stressful experience characterized by distressing symptoms that may persist for weeks or months following the loss. These manifestations typically decrease in intensity as acceptance of the death and its implications gradually occurs.<sup>5</sup> Similarly, Ortega<sup>6</sup> conceptualizes human grief as a natural, adaptive, and expected response to the loss of a loved one. Although grief itself is not a disease, the absence of adequate psychic elaboration and symbolic processing may lead to psychopathological outcomes, including depression, anxiety, or what is clinically termed complicated grief.

Not all grieving processes are experienced in the same way; therefore, their intensity and characteristics vary depending on the type of loss, making each experience unique to the individual. Grief commonly involves a range of emotions such as sadness, anger, denial, resignation, guilt, and love, which do not follow a strictly sequential or linear progression.

“The process of chronic illness and the potential life threat to a child generates feelings of uncertainty and profound distress in parents, described by some as the most stressful event of their life cycle.”<sup>7</sup> The loss of a child extends beyond the affective bond that unites them; it disrupts expectations of the future and what might have been, profoundly impacting parental identity. As caregiving

and protection constitute central aspects of parenthood, such loss is often experienced as an unnatural rupture that leads to existential emptiness.

Carreño et al.<sup>7</sup> identify six central themes emerging in parents of children who died from cancer. One of these is the loss of meaning, expressed as a profound disconnection from the desire to live, accompanied by intense emotions such as frustration, fear, and anger. These emotional states frequently lead to social withdrawal, addictive behaviors, suicidal ideation, and disruptive coping mechanisms. The remaining five themes—idealization, perpetual battle, unbreakable bond, spiritual struggle, and the process of rising and moving forward—reflect the deep pain and multidimensional dysfunction experienced by caregivers following the loss.

## METHODOLOGY

This article is based on an exploratory review of scientific literature aimed at identifying and analyzing relevant theoretical contributions on grief from the caregiver’s perspective. To broaden the analytical scope, one systematic review article was also included to provide a comprehensive overview of the topic. The selection criteria focused on studies published within the past 20 years, retrieved from databases such as SciELO, Redalyc, and Google Scholar, using keywords including *grief*, *anticipatory grief*, *caregiver grief*, and *caregiver mental health*. Qualitative studies were prioritized in order to capture the emotional and existential dimensions of grief among caregivers. No geographical restrictions were applied, allowing for an intercultural and more comprehensive understanding of the phenomenon.

## ANALYSIS

### Grief as a Natural Reaction

Grief is not classified as a mental disorder. Rather, it is a natural process triggered by a significant loss and may unfold through different phases characterized by intense emotional manifestations which, although they may resemble depressive symptoms, should not be equated with clinical depression.<sup>8</sup> Nevertheless, in some cases, grief may evolve into clinical conditions such as major depressive disorder, particularly when it does not follow an adaptive trajectory. Under such circumstances, professional intervention may be required. It is essential to recognize that grief is an individual, unique, and non-replicable process that serves an adaptive psychological function.<sup>9</sup>

Parental grief following the death of a child presents distinctive characteristics. As Alameda and Barbero<sup>10</sup> note, “the death of a child does not even have a specific term in the dictionary to describe or symbolize its loss” (p. 487). This absence reflects not only the magnitude of the emotional void it produces but also the social difficulty in naming and symbolizing such an experience.

Parents’ psychological adaptation to the loss of a child constitutes a profoundly complex and painful process. This experience disrupts not only emotional stability but also personal identity, sense of purpose, and the structural dynamics of the family system. Parental grief is often particularly intense and prolonged, as it compels parents to reconstruct their lives in the midst of a void that fundamentally disorganizes the expected trajectory of the life cycle.<sup>11</sup>

From this perspective, caregiver grief can be understood as a singular experience of profound suffering, marked by emotions that are often difficult to articulate. Feelings such as guilt—stemming from the perceived failure to protect the child—and helplessness in the face of an uncontrollable illness may prolong distress over time, deeply affecting daily functioning, interpersonal relationships, and even the individual's sense of identity. Although painful, these manifestations are part of an expected grieving process.

Alameda and Barbero<sup>10</sup> propose a classification of grief manifestations that facilitates a more comprehensive understanding of its complexity in these contexts. At the physical level, symptoms may include a sensation of emptiness in the stomach, hypersensitivity to noise, fatigue, muscular tension, sleep disturbances, and loss of appetite. Emotionally, grieving individuals commonly experience a wide range of affective states, including guilt, anger, helplessness, fear, and loneliness. At the cognitive and behavioral level, difficulties with concentration and attention, mental confusion, periods of hyperactivity or inactivity, and increased substance use may be observed. Socially, grief may lead to withdrawal and isolation, while at the spiritual level, many individuals undergo a process of questioning or reevaluating their core beliefs.

### Grief as a Pathological Process

Pathological grief is primarily determined by the intensity and duration of the emotional response.<sup>12</sup> This distinction allows for a deeper understanding of the different types of grief, each with specific characteristics that facilitate a more nuanced comprehension of the grieving process in relation to individual coping capacities and contextual factors.

Based on these characteristics, the most common types of grief observed in parents of children with cancer include the following:

#### Anticipatory Grief

Anticipatory grief refers to an emotional adaptation process that begins when parents start processing the impending loss prior to the child's death, typically following a severe diagnosis or unfavorable prognosis. In pediatric oncology, this form of grief is particularly prevalent. According to Pérez Trenado (n.d.)<sup>11</sup>, families undergo a process in which hope for recovery gradually diminishes, initiating a progressive acceptance of the inevitable. This emotional acknowledgment activates coping mechanisms aimed at mitigating the psychological impact of the loss.

Although anticipatory grief does not eliminate suffering, it may facilitate a more conscious elaboration of the experience, allowing families to plan actions that alleviate distress and attribute meaning to end-of-life accompaniment. As Pérez Trenado (n.d.) states, "The transition from curative to palliative care fills families with guilt and sorrow, and it is common for relatives to blame physicians for having failed, as well as to blame themselves or others for having lost the battle."<sup>11</sup>

#### Chronic Grief

Chronic grief refers to a prolonged grieving process that significantly impairs an individual's functioning. In such cases, the

bereaved person is unable to restructure life after the loss, remains emotionally anchored to the memory of the deceased, and may perceive attempts to resume daily activities as betrayal or disloyalty.<sup>12</sup>

#### Secondary Loss Grief

Secondary grief encompasses the additional losses that accompany the primary loss. These may include disruption of daily routines, changes in family roles, loss of identity as a caregiver, frustration of future projects, and deterioration of social relationships. This form of grief is complex and multidimensional, affecting several areas of life simultaneously.

#### Normal or Uncomplicated Grief

Normal grief manifests through expected reactions such as sadness, confusion, guilt, anger, denial, and physical discomfort, which typically diminish over time. From Bowlby's attachment theory perspective (as cited in Flórez, 2002)<sup>8</sup>, the grieving process can be divided into four phases:

1. **Numbing or Shock Phase:** characterized by disbelief, denial, and sometimes anger.
2. **Yearning and Searching Phase:** marked by persistent longing and recurrent thoughts about the deceased.
3. **Disorganization and Despair Phase:** reality begins to be acknowledged, but symptoms such as insomnia, appetite loss, and feelings of emptiness emerge.
4. **Reorganization Phase:** new bonds and activities are gradually established, allowing remembrance of the deceased with emotional ambivalence and progressive reintegration into daily life.

As Flórez (2002)<sup>8</sup> notes, "traditionally, grief lasts between six months and one year; some signs and symptoms may persist longer, and certain emotions or memories associated with the loss may accompany the bereaved throughout life."

#### Grief Elaboration

As discussed, grief experienced by caregivers of children with cancer is a complex process that permeates multiple personal and familial dimensions. Elaborating grief does not imply forgetting or minimizing the loss; rather, it involves resignifying it through love, enduring bonds, and psychological continuity. Within this framework, identifying guiding principles that support caregivers throughout their grieving journey becomes essential, fostering a more conscious and accompanied process.

The primary goal of therapeutic intervention in grief is to facilitate emotional adaptation and prevent the development of complicated grief.<sup>9</sup> According to this author, three basic levels of intervention can be identified: preventive interventions, psychological support, and grief therapy—the latter being indicated when previous strategies prove insufficient.<sup>9</sup>

Cabodevilla<sup>12</sup> argues that "the fundamental strategy in managing grief is to allow oneself time and permission to consciously engage in the process and restore balance" (p. 171). The author further

emphasizes that “most individuals are capable of coping with and adequately processing grief without professional assistance. Diagnostic and intervention decisions must be prudent to avoid interfering with a normal human process” (p. 171). From this perspective, emotional suffering following loss is recognized as a legitimate human response shaped by coping abilities, belief systems, and individual psychological resources. Therefore, any intervention must be ethical, respectful, and attuned to the singular rhythm of the grieving individual.

Several theoretical frameworks have sought to conceptualize and support the grieving process. One of the most widely applied models is Worden’s Four Tasks of Mourning (Worden, n.d.), particularly useful due to its emphasis on emotional validation.

The first task involves accepting the reality of the loss, not only cognitively but also emotionally. Defensive mechanisms such as denial may hinder this integration. Worden recommends symbolic rituals to facilitate acknowledgment of the absence.

The second task entails working through the pain of grief, promoting healthy emotional processing and encouraging expression rather than repression. Avoidance of pain may lead to complicated grief, whereas supported engagement—particularly through psychological accompaniment—fosters adaptive elaboration.

The third task consists of adjusting to a world without the deceased. This includes reorganizing daily life, assuming new roles, and responding to emotional, social, and practical demands that arise after the loss. The difficulty of this task largely depends on the degree of prior dependency and the availability of social support networks.

Finally, the fourth task involves emotionally relocating the deceased and continuing to live. Rather than implying forgetting, this task refers to establishing a new internalized bond with the memory of the deceased, allowing the bereaved to reengage with life with renewed meaning and purpose (Worden, n.d.).

## CONCLUSIONS

Grief in the context of pediatric oncology represents one of the most painful, complex, and transformative experiences faced by parents and caregivers. It is not solely the suffering associated with the loss of a child, but a profound rupture in parental identity and in the life project constructed around that child. This form of grief transcends the individual sphere, becoming an experience of deep existential, emotional, and social impact.

Understanding grief in this context requires recognizing it as a multifaceted process, with manifestations across physical, emotional, cognitive, social, and spiritual dimensions. Emotions such as guilt, helplessness, fear, and hopelessness do not follow a linear or predictable trajectory. Therefore, therapeutic support must be grounded in respect for the singularity of each lost bond and for the psychological timing required for individual elaboration.

The caregiver’s role becomes tensioned between the desire to protect and the experience of imminent loss, giving rise to anticipatory grief marked by emotional ambivalence. The transition from curative to palliative care is often accompanied by guilt and frustration,

making ethical, empathic, and compassionate support indispensable. Although anticipatory grief does not eliminate suffering, it may create space for meaning-making and emotional preparation for farewell.

In this scenario, caregiver self-care must be understood as an act of psychological preservation and reconstruction. Emotional well-being forms part of the grieving process itself; caring for oneself may also represent a way of sustaining the bond and attributing renewed meaning to it. The creation of safe and symbolically meaningful therapeutic spaces is essential to prevent the chronification of distress or the emergence of more severe emotional complications.

Elaborating grief does not mean forgetting; rather, it entails an internal reconstruction that allows the integration of absence and the reconfiguration of life around new coordinates of meaning. Models such as Worden’s Tasks of Mourning provide valuable guidance, provided they are applied with sensitivity to each individual’s subjective rhythm.

Ultimately, parental grief within pediatric oncology is not only an experience of loss; it is also testimony to profound love, unconditional devotion, and the human capacity to endure, symbolize, and continue living despite pain. Psychological intervention should not aim to close grief, but to accompany the individual through it—acknowledging that some losses are not overcome, but can be integrated with dignity, memory, and hope.

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