

The Silent Grief of Parents of Childhood Cancer Survivors

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Abstract

Childhood cancer is a devastating experience for any family, and even when a child survives, the emotional journey for parents may be far from over. Although the end of treatment is often framed as a moment of celebration, many parents continue to experience grief, fear, guilt, trauma, and social isolation long after treatment has ended. This article reflects on the often invisible grief carried by parents of childhood cancer survivors, drawing both on personal experience and on published literature. It argues that this grief is real, complex, and frequently unrecognized because it coexists with gratitude and relief. Greater awareness of this emotional reality is needed so that families can receive more understanding, compassion, and support during survivorship.

Keywords: *Childhood Cancer Survivorship, Parental Grief, Emotional Trauma, Psychosocial Support*

Introduction

Years ago, I went through the experience of my child's cancer. It was not easy - not during treatment and not in the years that followed. My child survived, and I am deeply grateful for that. But the grief I carried was real, and it stayed with me for a long time.

For the past decade, I have had the privilege of walking alongside other families on this same journey. I have learned so much from them - their strength, their fears, and the quiet, often invisible grief that many carry. I am sharing these words with a humble heart, simply hoping to raise awareness about this lesser-known kind of grief. My wish is that, as a society, we can begin to better understand the emotional reality of families whose children survive cancer, so that we can offer more empathy and help make their path a little gentler.

I want to be clear: this is not about comparing grief. The pain of bereaved parents is unimaginable and beyond comparison. What I do want to highlight is that there is also grief among parents of survivors. It may look different, and it often goes unrecognized, even by communities and health professionals, but it exists. And it deserves to be seen.

What Is Grief in This Context?

The Cambridge Dictionary describes grief as "to feel or express great sadness, especially when someone dies." Parents of childhood cancer survivors often experience what might be understood as complicated grief. They are not grieving a single loss. Rather, they have experienced many significant losses that together may lead to a prolonged and difficult grieving process.

They grieve many losses: the “normal” childhood and innocence their child missed, including birthday parties, school events, and milestones overshadowed by medical procedures, hospitalizations, and time lost while focused on treatment. The child and family have had to live a life very different from the expectations, plans, and choices they had before cancer. Families may lose stability through marital strain and disruptions to family life, and some parents grieve the professional and social lives they left behind. Many of us also deeply grieve the time we missed with our other children. These forms of parental grief are often ambiguous and difficult to express because they coexist with feelings of relief, gratitude, and happiness about survivorship.

Cancer Does Not End When Treatment Ends

Cancer stays with a family forever. Challenges and health issues do not end once active treatment is over, since medical checkups may last for several years. But beyond medical appointments, there are other aspects of cancer that may haunt parents for decades.

Wakefield et al. describe cancer treatment completion as a significant milestone. However, coming off treatment may also be a time of psychological vulnerability for parents. The authors found that while parents celebrate treatment completion, they can also experience significant distress, including fear of recurrence, fatigue, and loneliness. (2)

Coping With Loneliness and Uncertainty

Van Dongen-Melman et al. conducted a study in the Netherlands with parents whose child survived cancer. The results indicated that they experienced changes of a definitive and long-lasting nature. Uncertainty and loneliness were most often reported. These problems did not decline over time, indicating that many parents suffer in silence for years after treatment ends. By comparing their lives before and after treatment, parents reported several significant changes that deeply affected their quality of life: chronic anxiety, emotional exhaustion and burnout, marital strain or long-term family tensions, financial and occupational setbacks, social isolation, health problems such as chronic stress and sleep disturbances, and parenting challenges. These changes were not incidental, but long-lasting, and were mostly labeled as negative. (3)

Survivorship and Guilt

When your child survives cancer, you feel overwhelming gratitude, but often it comes tangled with a deep, quiet guilt. It is not something we talk about often, even among ourselves. But it is there, in the silent moments after hearing that another child did not make it. Personally, I am so grateful that my son is alive, and that I still have him with me, but there is also the memory of faces that should still be here. Names I still say in my heart. Why did my son survive, and others did not? This may sound irrational, but it is real, and I have met many parents who feel the same. These feelings do not make us ungrateful; they make us human.

“It’s extremely difficult struggling with survivor’s guilt when my son is doing so well, and so many other families whom I have come to know and love have lost a child to cancer,” wrote Lori Williams, a mother whose son Thomas survived a rare form of leukemia. (4)

Survivor guilt is very common among this group of parents. Parents often meet other parents on the oncology ward during their child’s treatment. Usually, they are the only people who can truly understand what each other is going through. Most of us can relate to the feeling when a child on the ward dies: there is a silence in the hall - not the usual quiet of a hospital ward, but a deep, aching absence. Everybody knows, but nobody mentions it. One day the room is empty, and the parents are not seen again. No goodbye, just a void. Somehow, we all carry on.

Another common form of guilt arises from the conflict of dedicating extensive time and attention to a child undergoing cancer treatment, often at the expense of the other children’s needs. The sense of guilt and perceived neglect can have lasting psychological effects on both the parent and the siblings left at home.

A study by Davies and O’Connor concludes that parents may also feel guilt about having left siblings at home while staying in the hospital with a child with cancer. Most parents in the study reflected on the guilt of being unable to care for their other children while caring for the sick child. One mother said, “so [sibling] did miss lots of contact ... I feel really guilty, incredibly guilty.” Another mother described how she felt she had “missed out” on parenting the siblings: “I felt like I was failing as a mum ... I know I did because I wasn’t there for them. Even when I was there, I wasn’t there, I was too busy thinking about [child with cancer] and worrying about [child with cancer].”(11)

Several mothers described how siblings felt that they had a closer bond with the child with cancer. One mother remembered one of her children saying, “[child with cancer] is the golden child,” while another recounted a sibling saying, “I think you love [child with cancer] a little bit more than me.”(11)

The study concludes that the impact on siblings is an issue of deep concern to mothers and seems to leave many of them with regret and guilt years after the end of treatment.

Fears

Even after successful treatment, the threat of a child’s cancer returning is a constant worry for many parents. Every doctor’s visit, or even a mild illness, can reignite old fears of relapse. This constant state of vigilance takes an emotional toll, and for some parents, the threat of cancer’s return is never entirely gone. Every minor symptom can trigger panic. Fear of relapse may continue to haunt parents even decades after treatment ends.

In 2011, Bruce Feiler, author and cancer survivor, coined the term “scanxiety” in a Time magazine article titled “Scanxiety: Fear of a Postcancer Ritual.” He described this ongoing anxiety as follows: “Scans are like revolving doors, emotional roulette wheels that spin us around for a few days and spit us out the other side.” (6) Feiler vividly described the emotional turmoil experienced while awaiting scan results. Most parents can relate to this feeling when waiting for their children’s test results.

Beyond recurrence, parents may also fear the long-term side effects of treatment, such as developmental delays, cognitive impairments, fertility issues, or secondary cancers. These uncertainties about their child’s future health and quality of life weigh heavily on their minds. A recent clinical review by Bhatia et al. (2023) showed that by age 45, more than 95% of childhood cancer survivors will experience one or more chronic health problems related to late effects of treatment. (7)

Even after active treatment is finished, there may still be considerable uncertainty about what the future might hold. Uncertainty becomes a constant companion. Will their child have a normal lifespan? How will they navigate adult life after such a traumatic childhood? Will the child face stigma or discrimination?

Trauma and PTSD

Just like soldiers returning from combat, parents may experience symptoms of post-traumatic stress disorder (PTSD). (8) Having faced the real possibility of a child’s death can be traumatic. Witnessing a child’s pain, anxiety, and distress - and knowing that the only way to save that child’s life is to put them through a long, painful, and aggressive treatment - can also lead to long-lasting trauma. Even in the best-case scenarios, when the child is in full remission, parental trauma can linger in subtle ways. (9) The stress and anxiety of potential relapse can keep parents from feeling fully at peace, preventing them from processing and healing from the traumatic period.

According to Ljungman et al., in a study conducted in Sweden, parents may report post-traumatic stress symptoms up to six years after the end of treatment. (5)

Some of the most common symptoms of PTSD are:

- Avoiding people, places, and thoughts that remind a parent of their child’s treatment.
- Being hypervigilant, or feeling constantly on alert.
- Difficulty falling or staying asleep.
- Irritability or angry outbursts.
- Difficulty concentrating.
- Intrusive recollections or dreams of the event, or feelings that the trauma is recurring (flashbacks).

“I woke up and my husband was sitting on the bed crying. He asked me to stay awake with him. He was sweating, breathing fast, and his heart was racing. He said he had had a flashback about our son’s cancer and was afraid he was losing his mind.” (10)

“A year or so after treatment, I was watching one of those St. Jude specials (I avoid them now). When one of the children’s IV pumps beeped, all the blood left my head, I got terribly dizzy, and I almost passed out.” (10)

Social Isolation and Misunderstanding

We, parents of childhood cancer survivors, often struggle with the fear that others do not understand the full extent of our emotional journey. Society generally views survival as a clear-cut victory, and parents may feel pressured to be nothing but grateful. However, behind the relief and joy, there is often a deep well of unresolved trauma that remains unseen or is misinterpreted by others.

We may avoid sharing our concerns or struggles because we worry that others will judge us for not simply feeling grateful or for appearing to dwell on the past. The world expects us to be grateful and happy, and while we may indeed feel those things, we may also be grappling with grief. This societal expectation of unwavering positivity can leave parents feeling misunderstood. They may withdraw socially, afraid of being judged or viewed as ungrateful for their child's survival, which can deepen feelings of isolation.

I have seen many parents of survivors weighed down by exceptionally high expectations about the future. Some feel they are expected to do more than the average person because their child overcame cancer. They may feel guilty for simply wanting to be themselves, without the added burden of outsized expectations.

Moving Forward: How to Help

Understanding that grief can exist even in the absence of death is crucial in supporting these parents. Offering a space where they can express their fears, sadness, and complex emotions without judgment is essential. Healing from the emotional toll of a child's cancer survival takes time. Parents may never fully "get over" the experience, but they can learn to integrate their grief into their lives in a healthy and productive way.

By acknowledging their pain and encouraging open conversations about their complex emotions, we can help parents navigate the post-cancer journey with greater peace and resilience. From my personal experience, I have learned that the following kinds of support may help:

- Listen without judgment: allow parents to talk about their feelings, even if those feelings seem contradictory.
- Avoid labeling them as "strong," "inspirational," or "brave," since these labels may create expectations about how they are supposed to feel or behave.
- Validate parents' emotions: let them know it is acceptable to feel grief, fear, and sadness, even after their child has survived.
- Encourage professional support: therapy and support groups can help parents process their emotions in a healthy way.
- Acknowledge the trauma: understand that the cancer experience was a form of trauma, and that its effects can be long-lasting.

Conclusion

Over the past few decades, the prognosis for childhood cancer has improved significantly. With higher survival rates, however, new questions emerge about the long-term emotional impact on those involved, especially parents.

During treatment, parents are consumed by the urgent task of keeping their child alive. Their energy and focus are directed almost entirely toward survival. But when treatment ends, many are met with an unexpected emotional aftermath. They may assume that survival will bring only joy, yet instead they are confronted with complex feelings of grief, loss, and disorientation. Grief for the life they once imagined for their child, and sorrow over the suffering they witnessed, are very real.

While the end of treatment is often marked as a time of celebration, it can also be the beginning of a quieter, less visible struggle. Parents must learn to live in a new reality shaped by both gratitude and lingering pain. The physical scars left on a child's body are often visible; the emotional scars carried by parents, however, are much harder to see. These invisible wounds deserve recognition and compassion, not only from society at large but also from healthcare providers and support systems that surround these families. Acknowledging this grief is a vital step toward truly supporting families after cancer.

Author Biography

Alejandra Méndez is a Chilean mother of a childhood cancer survivor. After going through that life-changing experience, she decided to devote herself to helping ensure that all children diagnosed with cancer have the opportunity to survive the disease. She is actively involved in local and international initiatives focused on improving the quality of life of patients, survivors, and their families. Alejandra currently serves as Vice President of Childhood Cancer International (CCI) and President-Elect 2026. She is a member of the PARC Committee of SIOP (Programme for Advancing Research Capacity for Pediatric Cancer Clinical Trials), representing the voice of parents and childhood cancer survivors. In addition, she serves on the Expert Committee of Foundation S for the My Child Matters programme.

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