

# "I tried to be the rock...but inside I was just crumbling": Grandparents' Lived Experiences of Their Grandchildren's Cancer Journey

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## Abstract

This study explores the lived experiences of grandparents when their grandchildren are diagnosed with cancer, using an existential phenomenological approach. The essence of their experience, summarized as "Weathered Yet Unwavering," highlights five themes: Emotional Whirlwind, Finding Strength Through Faith, At a Standstill/Moving Forward, Being There, and A Renewed Perspective. Grandparents emerged as pillars of support while often suppressing their personal suffering. These findings aim to inform family-centered care in pediatric oncology.

## Introduction

A cancer diagnosis in a child is a profound event that ripples through the entire family, altering roles, relationships, and emotional landscapes.<sup>1,2,3</sup> While much of the research in pediatric oncology has understandably focused on the experiences of the diagnosed child, their parents, and siblings, there is a **noticeable gap in understanding the roles and emotional challenges faced by grandparents.**<sup>4</sup> This gap exists despite grandparents often serving as critical pillars of support, providing stability and care to their adult children and grandchildren during times of crisis.<sup>5,6</sup>

Research indicates that the **emotional journey for grandparents is complex and multifaceted.**<sup>2</sup> Grandparents report experiencing intense emotions such as grief, fear, and helplessness—not just for their grandchildren but also for their own adult children who are navigating the diagnosis and treatment. This "doubled emotional response" uniquely situates grandparents at the intersection of multi-generational suffering.<sup>5,7</sup> Their roles may include caregiving, providing financial support, and filling in logistical gaps, such as caring for the diagnosed child's siblings or managing household responsibilities. **However, their needs, particularly psychological and emotional, are often overlooked** in both clinical and family care settings.<sup>5,6</sup>

Previous research has highlighted that grandparents, while seen as secondary caregivers, face significant challenges.<sup>4,5,6</sup> Many grandparents report struggling with their own health while also supporting their families.<sup>7</sup> In some cases, cultural expectations further compound their responsibilities, as they take on multiple caregiving roles simultaneously.<sup>5,7</sup> Despite these contributions, **family-centered care models in pediatric oncology often neglect the experiences and well-being of grandparents,**<sup>1,4</sup> leaving a critical void in holistic care for the affected family unit.

The current study addresses this gap by exploring the lived experiences of grandparents who have faced the reality of a grandchild diagnosed with cancer. Through an existential phenomenological approach, **the study seeks to uncover the lived experiences a childhood cancer diagnosis has on grandparents and to understand how they navigate their roles within the family during such a tumultuous time.**

Table 1. Descriptive statistics of study participants (N = 7)

	Grandparent Status	Age Range	Race/Ethnicity	Employment Status	Level of Education	Marital Status	Type of Cancer	N of Children	No. of Grandchildren	Rural, Urban, or Suburban
Ada	Grandmother	55-64	White	Full Time	4-year degree	Married	AML	2	2	Rural
Barbara	Grandmother	55-64	White	Full Time	Some college	Married	Osteosarcoma	1	8	Rural
Carol	Grandmother	65-74	White	Retired	2-year degree	Married	Ewing's Sarcoma	3	5	Rural
David	Grandfather	65-74	White	Retired	4-year degree	Married	Ewing's Sarcoma	3	5	Rural
Ellen	Grandmother	65-74	White	Retired	2-year degree	Widowed	Lymphoma	2	4	Rural
Fay	Grandmother	55-64	White	Part Time	Some college	Married	Osteosarcoma	2	5	Rural
Gail	Grandmother	65-74	White	Retired	High School	Married	Osteosarcoma	3	8	Suburban

## Methodology

An **existential phenomenological method** developed by Thomas and Pollio<sup>5</sup> was employed for data collection and analysis. Seven grandparents were recruited from the Southeastern United States via **purposive and snowball sampling.** One-on-one interviews were conducted using a HIPAA-compliant platform and analyzed for meaning units, themes, and existential contextualization. IRB approval and informed consent were obtained prior to data collection and analysis.

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## Results

Five major themes emerged from the current study:

- **Emotional Whirlwind:** "You just have every emotion you can think about..."
  - **Shock/Disbelief:** "I just screamed, and I fell to the floor; I just couldn't believe it."
  - **Fear/Uncertainty:** "We're all frightened...we don't know if he's gonna survive."
  - **Compounded Helplessness:** "Seeing your child struggle with their child having to go through something so horrible."
  - **Grief/Loss/Heartbreak:** "There's an overwhelming sense of sadness and loss."
  - **Guilt:** "There is some survivor's guilt because they didn't all make it through..."
- **Finding Strength Through Faith:** "My faith was what gave me hope."
- **At a Standstill/Moving Forward:** "You can't look back. You can't look forward. You just got to put one foot in front of the other and do one day at a time."
- **Being There:** "Just being there for her, I hope, helped her to get through this."
  - There to Give and Receive Support: "You can't do life alone."
  - There to Fill a Role: "As a grandparent, you just try to be all things to all people."
  - There Selflessly: "You don't take care of yourself very much."
- **A Renewed Perspective:** "It's changed the way I look at life..."

Figure 1. Diagram of thematic structure of grandparents' lived experiences of their grandchildren's cancer journey



## Discussion

The findings from this study highlight the **profound impact of a child's cancer diagnosis on grandparents**, who often serve as unwavering pillars of support amidst their own emotional turmoil. The **emotional whirlwind experienced by grandparents underscores the complexity of their suffering**, magnified by witnessing the pain of both their grandchild and their grown children. **Compounded helplessness and multiplied suffering** emerge as critical themes, emphasizing the necessity for healthcare teams to acknowledge and address the unique challenges faced by grandparents.

A noteworthy finding is the significant **role of spiritual faith in helping grandparents navigate these challenging circumstances.** Their faith provided a source of hope and resilience, enabling them to persevere despite fear, uncertainty, and grief. This insight suggests that integrating faith-based support into clinical care could be beneficial, especially in regions where religiosity is prominent. These results align with existing literature on the emotional struggles of grandparents in the context of pediatric cancer but provide a unique perspective through the existential phenomenological lens applied in this study.

This study underscores the **critical need to extend family-centered care practices to include grandparents as integral members of the caregiving team.** By understanding their lived experiences, healthcare providers can better meet their psychosocial and spiritual needs. Recommendations resulting from this study include enhanced communication, faith-based support, role acknowledgment, education and training, and future research.

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