



# Beyond the Unknown: Navigating the Transformative Journey of Caregiving through Rare Cancer

**Bistis-Nadala CR<sup>1,2\*</sup>**

<sup>1</sup>Psychoanalysis (Psychoanalyst in Training), Greater Kansas City Psychoanalytic Institute, USA

<sup>2</sup>Department of Psychiatry, West Visayas State University, Philippines

**\*Corresponding author:** Christine Rio Bistis-Nadala, Department of Psychiatry, Psychoanalysis, West Visayas State University, Philippines, Greater Kansas City Psychoanalytic Institute, MO, USA, Tel: +1402-499-0385; Email: [drcrjbistisnadala@gmail.com](mailto:drcrjbistisnadala@gmail.com)

**Investigation Paper**

**Volume 8 Issue 1**

**Received Date:** January 10, 2024

**Published Date:** January 31, 2024

**DOI:** [10.23880/mhrij-16000237](https://doi.org/10.23880/mhrij-16000237)

## Abstract

This article explores the intricate journey of caregiving amid the complexities of rare cancer, emphasizing the transformative impact on individuals and family dynamics. Told through the lens of the author—a doctor, psychiatrist, and current psychoanalyst in training, as well as a sibling and caregiver—it explores the investigative, treatment, and acceptance phases. This narrative serves as a case study, reflecting the author's personal journey through the complexities of caregiving in the context of rare cancer. Highlighting the importance of grief processing and honoring the autonomy of the sick, the article explores the underlying reasons behind the caregiver's desire for control. Advocating for self-care as a significant factor, it provides a list of practical strategies and closes by underlining the step-by-step process of acceptance. It underscores the diverse journey of caregiver navigating rare cancer, weaving together life's complexities with resilience, love, and the enduring power of the human spirit.

**Keywords:** Rare Cancer; Monochromatic Synovial Sarcoma; Oral Chemotherapy; Caregivers

## Introduction

In the tapestry of life, there are threads that unravel unexpectedly, leading us through uncharted territories. This is the intimate narrative of our family's journey navigating the intricacies of rare cancer, a journey that profoundly transformed us as individuals and as a family unit. At the heart of this narrative is BBoy, the youngest and only son among three siblings, whose diagnosis of monochromatic synovial sarcoma stage IV in May 2015 marked the genesis of a transformative expedition. This article delves into the nuances of caregiving, emphasizing the imperative of processing grief, respecting the autonomy of the sick, and managing the anxiety born from uncertainties [1].

## The Investigative Phase: Unraveling the Unknown

In the initial throes of BBoy's illness, the landscape of uncertainty was a labyrinth that demanded navigation. As the only doctor among siblings, I found myself straddling the line between professional detachment and personal turmoil. The unsettling period of awaiting a diagnosis, coupled with the revelation of a rare and advanced cancer, defined what I now refer to as the "when life becomes precious" phase—a crucible for personal growth as a caregiver.

During this phase, the paramount importance of family support and unwavering faith in God or higher being became

evident. Coping mechanisms such as mindfulness, prayer, and seeking support from mentors and loved ones emerged as pillars of strength. The experience illuminated the therapeutic value of embracing vulnerability, acknowledging the grim prognosis while recognizing that cancer is not an irreversible sentence.

### **The Treatment Phase: Navigating the Minefield**

The subsequent treatment phase unfolded as a litmus test for our family's resilience. BBoy endured 22 months of both intravenous and oral chemotherapy, propelling the family through a minefield of uncertainties. Conflicts arose as we grappled with the innate desire to control the uncontrollable. Yet, the essential support found within the Psychiatry department and the valuable guidance from mentors played a crucial role, especially given that I was still undergoing my psychiatry residency training during this period [2]. Celebrating small victories and finding joy amid adversity became wellsprings of strength.

In the midst of treatment, BBoy decided to marry, choosing joy and happiness amidst the struggle. This decision underscored the importance of celebrating life's ephemeral moments and finding courage in the face of adversity.

### **Embracing Fate: The Final Phase**

As BBoy's health declined, he displayed bravery by opting to abstain from additional aggressive medical interventions and embrace his fate. Witnessing his acceptance was both heart-wrenching and enlightening. The role of a caregiver transitioned from attempting to control the inevitable to respecting his autonomy and choices. Returning to our hometown provided a canvas for a transformed perspective on life, as BBoy found joy in simple things, like learning to drive a car and smiling despite the challenges.

As his condition worsened, my role evolved from being a sister to an objective caregiver. Assisting in planning his funeral, I discovered the strength derived from acknowledging the inevitability of life's end. BBoy's suffering became sacred ground, allowing our family to share in the suffering of Christ and surrender to His will.

### **Acceptance and Personal Transformation**

The most challenging facet of this journey was aiding my parents, sister, and sister-in-law in accepting the reality of BBoy's impending departure. The calmness and resilience exhibited by mentors and loved ones became a guiding light, and I assumed the responsibility of supporting each family member through their unique grief process.

In conclusion, this caregiving journey transcended the physical care of a loved one, evolving into a profound personal transformation. Learning to care for oneself, embracing the uncertainties of life, and finding inspiration amid suffering became invaluable lessons. This experience encourages all caregivers to view their journey as an opportunity for personal growth, honest conversations, and self-care [3].

### **Processing Grief and Respecting Autonomy: The Cornerstones of Effective Caregiving**

Grief, an inevitable companion on the caregiver's journey, is a multifaceted emotion that demands acknowledgment and processing. The need to process grief is particularly pronounced when faced with a terminal illness like cancer. Caregivers often find themselves oscillating between hope and despair, love and loss. It is crucial to recognize that the process of grieving is not linear but rather a dynamic, ever-evolving experience.

Respecting the autonomy of the sick is another pivotal aspect of effective caregiving. In the face of life-altering decisions, the patient's autonomy should be preserved and honored. BBoy's decision to forego further treatment and embrace his fate exemplifies the importance of recognizing and respecting the patient's agency in determining their path.

### **Understanding the Roots of the Need for Control**

The compulsion to control every aspect of the situation is a common response to the uncertainties and anxieties that accompany caregiving. Both caregivers and patients grapple with the unknown, and the need for control becomes a coping mechanism. However, it is imperative to recognize that some elements are beyond control, and attempting to micromanage every detail can lead to increased stress and burnout.

Effective caregiving necessitates knowing one's boundaries and managing personal anxieties arising from the unknown. Establishing a balance between being proactive and recognizing the limitations of control is essential for the well-being of both the caregiver and the patient.

### **Self-Care as a Radiant Force**

Caregivers often neglect their own well-being in the relentless pursuit of providing care. Yet, the caregiver's mood and emotional state profoundly influence the patient's experience. Understanding that communication between the right and right brain is vital, caregivers should prioritize self-care to radiate positivity and resilience.

### Enumerating Different Ways of Self-Care for the Caregiver

**Take Time for Solitude:** Even in the midst of chaos, carve out moments of solitude. Whether it's a short walk, reading a book, counting your breaths, or simply sitting in silence and doing bompū zen, these moments provide an essential recharge.

**Maintain a Journal:** Documenting thoughts and emotions in a journal can be therapeutic. It provides an outlet for expression and serves as a reflective tool for personal growth.

**Reach Out for Support:** Establish a network of support. Share your experiences with friends, family, or support groups. Sometimes, the simple act of sharing can alleviate the weight of the burden.

**Celebrate Small Victories:** Acknowledge and celebrate even the smallest achievements and positive moments. These celebrations act as beacons of light in the caregiving journey.

**Learn to Laugh:** Humor is a potent antidote to stress. Find moments of levity, share laughter with the patient, and allow humor to permeate the caregiving environment.

### Facilitating the Process of Acceptance

Acceptance is a gradual process, and caregivers play a pivotal role in guiding the patient through this journey. It involves acknowledging the inevitability of the situation, finding meaning in the experience, and embracing the present moment. Facilitating acceptance requires empathy, patience, and a willingness to share in the patient's emotional landscape.

### Conclusion

The caregiver's journey through rare cancer is a multifaceted expedition that demands resilience, self-awareness, and a deep understanding of the emotional intricacies involved. Processing grief, respecting the autonomy of the sick, and managing the need for control are essential elements in effective caregiving. Recognizing the roots of the compulsion to control, establishing boundaries, and prioritizing self-care contribute to a positive caregiver experience, which, in turn, radiates positivity to the patient.

In the tapestry of caregiving, acceptance becomes the final thread, weaving together the complexities of life, love, and loss. As caregivers, our ability to navigate the uncharted territories is not only a testament to our strength but also an opportunity for profound personal transformation. In honoring the autonomy of the sick, embracing vulnerability, and finding solace in the unknown, we discover that, even in the face of rare cancer, life's journey continues to unfold with lessons, love, and the enduring power of the human spirit.

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