

Ephemeral Threads: Weaving Emotions and Embodiment in Terminal Cancer Care

Hilos efímeros: Tejiendo emociones y encarnación en el tratamiento del cáncer terminal

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Abstract

This article explores the experiences of patients undergoing palliative cancer treatment, with a focus on how they perceive and manage their health meanings and emotions in a complex, embodied context. The research is based on narratives from individuals receiving treatment at the outpatient department (OPD) of Crescent Valley Oncology Institute in Kolkata (a fictionalized name for ethical reasons). Given the lack of a clear sample frame of cancer patients, the study focuses on terminally ill cancer patients who visited the OPD between April and July 2005. The study employs in-depth qualitative research interviews to understand how each patient's experience of illness is shaped by their perception of their body, emotions, and its changes in the palliative care setting. The theoretical approach proposed in this study is the "Managing Meanings of Embodied Experiences" (MMEE) framework. MMEE is a three-fold framework that delves into how individuals navigate and interpret the meanings of their health experiences and emotions. The study examines how patients' body-selves are intertwined with their relationships with others, biomedical interventions, and the ongoing, dynamic nature of their physical, emotional, and psychological experiences. A key finding is that patients' embodied experiences and emotions are not static; rather, they evolve as they cope with their illness, make choices, and incorporate these experiences and emotions into their identities and relationships. This reflects what is termed the body-self-society 'triad,' showing that the self, body, and emotions are in constant interaction with society and its medical structures.

Keywords: Embodied Experience; Palliative Care; Illness Experience; Dying; Uncertainty.

Resumen

Este artículo explora las experiencias de pacientes sometidos a tratamientos paliativos contra el cáncer, centrándose en cómo perciben y gestionan sus significados y emociones relacionados con la salud en un contexto complejo y corpóreo. La investigación se basa en las narraciones de personas que reciben tratamiento en el departamento ambulatorio del Crescent Valley Oncology Institute de Calcuta (un nombre ficticio por razones éticas). Dada la falta de un marco de muestra claro de pacientes con cáncer, el estudio se centra en pacientes con cáncer terminal que visitaron el departamento ambulatorio entre abril y julio de 2005. El estudio emplea entrevistas de investigación cualitativa en profundidad para comprender cómo la experiencia de la enfermedad de cada paciente está determinada por su percepción de su cuerpo, sus emociones y sus cambios en el entorno de cuidados paliativos. El enfoque teórico propuesto en este estudio es el marco de "Gestión de los significados de las experiencias corpóreas" (MMEE). MMEE es un marco triple que profundiza en cómo las personas navegan e interpretan los significados de sus experiencias y emociones relacionadas con la salud. El estudio examina cómo el yo corporal de los pacientes se entrelaza con sus relaciones con los demás, las intervenciones biomédicas y la naturaleza dinámica y continua de sus experiencias físicas, emocionales y psicológicas. Un hallazgo clave es que las experiencias y emociones corporales de los pacientes no son estáticas, sino que evolucionan a medida que afrontan su enfermedad, toman decisiones e incorporan estas experiencias y emociones a sus identidades y relaciones. Esto refleja lo que se denomina la "tríada" cuerpo-yo-sociedad, que muestra que el yo, el cuerpo y las emociones están en constante interacción con la sociedad y sus estructuras médicas.

Palabras claves: Experiencia encarnada; Cuidados paliativos; Experiencia de enfermedad; Morir; Incertidumbre.

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Introduction

In recent years, the notion of death's medicalization has gained increasing attention. Across cultures, death has been accompanied by rituals and traditions that celebrate life, strengthen communal bonds, and offer solace. However, in the Global North, death has largely moved from the family's embrace into the sterile environment of hospitals. A similar shift is unfolding in Indian cities. Though the hospice movement has deep roots in 19th-century Europe, its presence in India is relatively new.

Listening to the stories of the terminally ill offers profound insights into their inner worlds as they either cling to hopes of bodily recovery or seek fresh meanings and purposes in life. This paper draws on the narratives of patients receiving palliative cancer treatment at an OPD unit in Kolkata, exploring how those grappling with serious illness re-imagine their pursuits of purpose and meaning. For the dying, part of the healing journey lies in discovering how to live anew within a world that is rapidly transforming around them. Dominant sociological thought traditionally defines illness as "a state of disturbance in the 'normal' functioning of the total human individual, including both the state of the organism as a biological system, and of his personal and social adjustments. It is thus partly biologically and partly socially defined" (Parsons, 1951, p. 431). This paper, however, moves beyond such frameworks by deeply "listening" to patients' lived experiences. Illness unfolds on multiple planes—biological, psychological, medical, and social—forming an intricate hierarchy of symptoms. Its progression is first shaped by social and cultural beliefs, only to be later claimed by scientific explanations during medical encounters (Brody, 1987).

The models of illness and recovery proposed by Parsons (1951) and Brody (1987) fail to capture the unique social role of the dying (De Spelder &

Strickland, 1992). While the social function of death may be undefined, those facing their end expect the living to behave according to certain unspoken rules. They are urged to follow a ritualized passage towards death, often marked by expectations of its timing (Glaser & Strauss, 1965). The dying are encouraged to present themselves as healthy to comfort those who are uneasy with their decline.

Scholarship has recently turned its gaze toward the dying experience, making a critical distinction between death and dying, which are too often conflated. As Hicks (2012) eloquently reflects,

We have all seen her. Many of us see her several times a week, though her name may have changed. She lies in a hospital bed, dressed in a nightgown, pale, old, thin or overweight, either silent or chatty, sharp-minded or confused. Her prime may have been many years ago, or perhaps just last week. We do not see her hopes, fears, achievements, memories, loves, or losses. Instead, we see her chest X-ray, ECG, FBC, U&Es, and LFTs. We admit her on our forms, note her next of kin, treat her pneumonia according to antibiotic protocols, assess her VTE risk, manage her heart failure, monitor her kidney function, review her long list of medications, and struggle to find her a bed... She is dying, but she is not dead. She is alive to new experiences: to pain, hope, and fear (Hicks, 2012, p. 106).

This paper takes up the challenge of delving into these untold experiences, seeking to give voice to those often left unheard and unwritten. It strives to illuminate the profound, subjective realities of those nearing the end of life, offering a more nuanced understanding of the journey through dying.

Methodology

This research employed a qualitative design

to examine how terminally ill cancer patients interpret and cope with their physical and emotional experiences within a palliative care context. The study was conducted at the Crescent Valley Oncology Institute (a fictionalized name for ethical reasons) in its outpatient department (OPD) from April to July 2005. Due to the lack of a formal registry for terminally ill cancer patients, purposive sampling was applied selecting participants based on their recent OPD visit and treatment stage.

Sampling Criteria and Timeframe Rationale

The study focused on terminally ill patients who had received palliative care at the OPD during the April–July 2005 period. This window provided an optimal sample size and aligned with a stable period in the facility’s staffing and resources, allowing for consistency in care conditions. Patients selected met clinical criteria indicating a terminal prognosis, as determined by treating oncologists. Focusing on this advanced stage of illness allowed for an in-depth exploration of how patients navigate the reality of a terminal condition and make meaning of their embodied and emotional experiences.

Data Collection: Semi-Structured Interviews

We utilized semi-structured, in-depth interviews to capture participants’ views on their physical and emotional experiences. This approach encouraged participants to share their stories and perspectives freely, allowing for an in-depth understanding of their evolving body awareness and emotions. Interview prompts were organized to cover several critical areas:

Perceptions of the Body: Participants were asked questions that focused on their experience of bodily sensations, symptoms, and physical transformations due to cancer and treatment. For instance, they were encouraged to discuss specific physical changes and how these impacted their sense of identity and daily functioning.

Emotional Shifts and Awareness: Participants were invited to reflect on their emotional journey, describing how their emotions had shifted over time and how they managed these changes. This included emotions such as fear, hope, or acceptance and how these emotional states intertwined with their physical experiences.

Social and Relational Dynamics: Recognizing that bodily experiences often intersect with social

relationships, patients were asked to share how their connections with family, friends, and healthcare providers influenced their experience of illness and sense of self. This included discussing what aspects of their physical and emotional experiences they shared or kept private with others.

Analytical Approach: Thematic and Interpretive Analysis

The analysis was guided by the “Managing Meanings of Embodied Experiences” (MMEE) framework and used a thematic and interpretive approach. We coded interview transcripts to capture recurring themes about patients’ understanding and responses to their physical and emotional experiences. These codes were then grouped into broader themes aligned with the MMEE framework, focusing on patterns in how patients make meaning of their illness.

Using the body-self-society 'trialectic' model, we examined how patients’ physical, emotional, and social realities shaped their illness experience. In particular, we analyzed sections of narratives describing the interaction between physical sensations, emotional responses, and the influence of social relationships. This model allowed us to capture the complex, evolving interplay between the patient’s embodied experience, personal identity, and surrounding medical and social structures.

Applying the MMEE Framework

Within the MMEE framework, three key domains were examined:

1. **Understanding Embodied Meanings:** This dimension focused on how patients interpret physical symptoms and bodily changes.
2. **Emotional Resilience and Adaptation:** We explored how patients managed evolving emotions, particularly in how they adjusted emotionally to their condition and found ways to cope.
3. **Relational and Social Embodiment:** This domain addressed how interactions with family, caregivers, and medical personnel affected patients’ perceptions of their bodies and sense of self.

Analyzing patient narratives through these three lenses helped trace the progression in physical and emotional experiences as patients adapted to their illness and the social context around them. The body-self-society 'triad' approach within the MMEE

framework illustrated the fluid interconnections between these aspects, revealing patterns in how patients integrated their physical, emotional, and social experiences over time.

To enhance the study's rigor, researchers kept reflexive journals during data collection and analysis to acknowledge potential biases. Member checks were conducted with select participants to confirm that the findings accurately represented their perspectives. This reflective process strengthened the reliability of insights and ensured interpretations closely aligned with participants' lived experiences. Utilizing this comprehensive methodological approach, the study sheds light on the intricate, evolving nature of terminal cancer patient's physical and emotional journeys, offering a valuable contribution to understanding health communication and support strategies in palliative care.

A step-by-step outline of the thematic analysis process, followed by a clear description of how the interpretive method was incorporated to deepen understanding of patients' narratives is given here:

Thematic Analysis Process

The thematic analysis followed a structured approach to identify and categorize patterns across participants' narratives, focusing on their physical and emotional experiences within the palliative care setting. This process involved several stages:

1. **Familiarization with Data:** The research team conducted multiple readings of interview transcripts to become immersed in the patients' narratives, paying attention to recurrent descriptions of physical sensations, body awareness, emotional responses, and social interactions.

2. **Generating Initial Codes:** Using line-by-line coding, researchers assigned descriptive labels to segments of data that conveyed meaningful information about the patients' embodied experiences, emotions, and interpersonal dynamics. For example, codes like "bodily discomfort," "emotional adjustment," and "social connection" were applied to identify key experiences.

3. **Developing Themes:** Once initial codes were established, related codes were grouped to form broader themes. Themes were selected based on their relevance to understanding the physical and emotional aspects of the illness experience. Key themes that emerged included "Navigating Physical Changes," "Emotional Resilience," and "Impact of Relationships."

4. **Reviewing and Refining Themes:** The themes were then reviewed against the dataset to ensure they accurately represented patients' experiences. This involved reassessing the themes to ensure coherence within and distinctiveness between them.

5. **Defining Themes:** Each theme was given a clear definition to guide subsequent analysis and ensure consistency. For instance, "Navigating Physical Changes" focused on how patients perceived and coped with changes in their bodies, while "Emotional Resilience" explored adaptive responses to emotional challenges.

The interpretive method was applied to analyze the underlying meanings and subjective significance of patients' experiences beyond the surface-level themes. This involved interpreting how patients' responses reflected deeper aspects of their evolving identities, self-concepts, and relational dynamics. Specifically:

1. **Contextualizing Narratives:** Researchers examined each narrative in its broader context, considering personal, social, and cultural factors that might shape patients' experiences and perceptions of their bodies and emotions.

2. **Exploring Personal Significance:** The interpretive approach was used to delve into patients' meanings and interpretations of physical symptoms and emotional shifts. For instance, rather than merely noting "fear" as an emotional theme, the interpretive analysis sought to understand how patients' expressions of fear related to their sense of identity, loss of control, or existential concerns.

3. **Connecting to the MMEE Framework:** The interpretive method also facilitated the application of the MMEE framework by helping researchers understand how patients' meanings of their bodies and emotions evolved in response to their illness, choices, and social contexts. This process allowed for an exploration of the "body-self-society triad," illustrating how patients' identities and emotions were shaped in tandem with their embodied experiences and social relationships.

By combining thematic and interpretive approaches in this way, the analysis uncovered not only what patients experienced but also how they made sense of and integrated these experiences into their lives. This combination of methods revealed nuanced patterns that highlighted the complex and fluid nature of patients' embodied and emotional journeys in a palliative care setting, providing deeper insights into their coping processes and sense-making strategies.

Scripting Survival Beneath the Burden: The Resilient Voices

The language of medicine and illness is rich with expressions, sentiments, and experiences that portray the body as a fountainhead of creativity (Good, 1994). According to Good, narrative plays a crucial role in the reciprocal processes of both personal and social efforts to resist dissolution and reassemble meaning in life. People weave their stories together to find answers to their ailments. By narrating their experiences and becoming increasingly aware of their bodies and the changes they undergo, individuals embark on a profound search for understanding.

In a dimly lit hospital room, a middle-aged woman named Raima (a fictional name to preserve anonymity) sits propped up by pillows, her frail form wrestling with the ravages of cancer. Hailing from a lower-middle-class family in the small town of Barasat, West Bengal, she never envisioned herself facing such a formidable foe. Yet here she is, not only contending with the disease itself but also with the profound transformations it has inflicted upon her body. As her illness advances, Rani becomes acutely aware of every subtle alteration—a stark reminder of her mortality.

"My once formidable frame now feels like a delicate shell," she breathes softly, her fingertips gliding over the sharp outlines of her protruding bones, now starkly visible beneath the pallid skin stretched taut by the weight of her suffering. The chemotherapy surges through her veins like a double-edged sword, valiantly battling the cancer while simultaneously sapping her strength and rendering her emaciated. Each day unfolds with fresh tribulations as she confronts the unrelenting siege on her body, grappling with the heart-wrenching loss of her hair, the vise-like grip of nausea that ensnares her, and the insidious fatigue that looms, ready to consume her whole. Yet, within this whirlwind of chaos, ephemeral moments of tranquil reflection arise, offering her solace in the indomitable resilience of the human spirit and in the unbreakable bonds forged with her steadfast loved ones—her devoted wife and family—who stand unwaveringly by her side.

In the vibrant tapestry of Kolkata, Jayita, a courageous single mother in her late thirties, finds herself ensnared in a fierce struggle against the insidious grip of breast cancer. Having grown up amidst the lively rhythm of a working-class neighborhood, she has long been familiar with the frenetic pulse of urban life, yet nothing could have prepared her for the profound metamorphosis that

cancer would impose upon her existence. "My body has transformed into an alien terrain," she confides, her voice laced with a bittersweet resignation. As the malady takes root, she wrestles with the heavy toll it exacts, her once exuberant spirit surrendering to the relentless waves of fatigue and the unwelcome pangs of pain. The harsh reality of chemotherapy manifests as her hair cascades down in clumps, a poignant reminder of the internal battleground raging within her. Yet, amid the tempest of adversity, Jayita discovers moments of unexpected grace—fleeting glimpses of resilience that lie hidden beneath the surface. "Though I may be bruised and battered, I remain unbroken," she asserts, her eyes sparkling with a fierce determination. Drawing strength from the boundless love of her children and the steadfast support of her community, Jayita resolutely continues her fight, defiantly refusing to allow cancer to dictate her identity or chart the course of her future.

Jayita's story also poignantly illuminates the financial burdens that cancer imposes, serving as a stark reminder of the myriad challenges she must confront. As a single mother traversing the treacherous waters of cancer treatment, she wrestles not only with the physical and emotional toll of her illness but also with the crushing weight of financial strain. The costs of chemotherapy sessions, medications, and specialized care accumulate, pressing heavily on her mind and casting a shadow over her already arduous journey. In reflecting on these expenses, Jayita finds herself grappling with heart-wrenching decisions and sacrifices, skillfully navigating the precarious balance between pursuing the best possible care for herself and safeguarding the well-being of her beloved family.

The "Managing Meanings of Embodied Experiences" (MMEE) framework offers a three-dimensional approach to understanding how individuals navigate the experience of serious illness. This model emphasizes the continuous, dynamic relationship between the body, self, and emotions, each interacting with the others as patients manage the challenges of illness, such as those faced by Jayita. Through the MMEE lens, the process of "being" and "doing" takes on unique dimensions within the context of palliative care, where patients not only endure physical symptoms but also reinterpret their identities, emotional resilience, and connections to others. In the first dimension, *embodied meanings*, patients like Jayita redefine their relationships with their bodies as their physical state changes. The "alien terrain" Jayita describes reflects her perception of a body transformed by illness and treatment. As she encounters fatigue and pain, her experiences become

part of a new bodily reality she must learn to interpret and understand within her new context. The second dimension, *emotional adaptation*, involves how patients manage the emotional challenges of illness while reconfiguring their sense of self. Jayita's narrative reveals both despair and resilience; she feels the toll of the illness yet discovers moments of strength and defiance. This emotional journey highlights her transition from a life shaped by external demands and roles to one that also includes the introspective experience of grappling with an unpredictable, life-threatening illness. The third dimension, *social embodiment*, emphasizes the importance of relational support and social context. Jayita's story illustrates how her social connections—her children, community, and support networks—act as a source of strength, anchoring her and reinforcing her resolve to confront cancer. This dimension shows that embodied experiences are not solely personal; they are influenced by and intertwined with relationships, which provide emotional and practical support as she navigates financial, emotional, and physical challenges. The MME framework thus reveals how the synthesis of “being” and “doing” transforms within palliative care. Jayita is both a caregiver and a patient; she faces financial decisions while fighting for survival. Her resilience grows out of an interplay between her self-perception, physical limitations, and the social bonds that reinforce her determination, illuminating the powerful, multifaceted process of coping and adaptation through the interconnected realms of body, self, and emotions.

As Rani and Jayita share their deeply personal experiences with friends, family, and medical professionals, they come to understand that the interpretation of their narratives varies significantly depending on the audience. Each retelling breathes life into their stories, shaping and reshaping them as they are conveyed. While the physician's primary aim is to diagnose a medical condition, the patient's quest lies in seeking understanding and meaning in their illness. Yet, within the rituals of medical interactions—spanning diagnosis, treatment, and prognosis—much of the intimate essence of these narratives remains unvoiced (Davey & Seale, 2002). As individuals grapple with their experiences, their sense of embodiment undergoes profound transformations, urging them to either embrace a new way of life or adapt to one that is thrust upon them (Frank, 1995).

Charting the Abyss: Musings on Mortality and Inner Strength

To occupy the intricate tapestry of social and cultural realms, the pursuit of physical well-being transforms into a formidable endeavor, often leaving a scant opportunity for reflection on the transient nature of existence. The human form, a magnificent product of evolution, finds itself shaped by both social interactions and biological occurrences, the latter leaving an indelible mark on the body as it matures. The specter of death becomes a poignant reality when the corporeal vessel resists reconstruction (Shilling, 2002).

As Merleau-Ponty eloquently posits, the body does not engage with the world it inhabits through an objective lens, but rather through a deeply subjective experience. Illness instigates a profound sense of estrangement, as one shifts from being a participant in the world to embarking on an inward journey to navigate and reestablish a connection with an alien reality (Samson, 1999). When biomedicine exceeds its boundaries and the delicate transition to palliative care unfolds, a further layer of mediation is required once this arduous negotiation and reconnection has been achieved. The institutional policies surrounding death and dying reveal that the social framework of mortality is intricately woven into the fabric of these establishments. Death, once a natural part of the human experience, has been relegated to the shadows, its processes medicalized and obscured (Sudnow, 1967). In this manner, the act of dying transforms into a commodified experience, where the individual in their final moments becomes a consumer of medical and palliative care, alongside funeral services, while death itself remains shrouded in silence.

Turning one's gaze inward amidst the tribulations of illness can cultivate a profound sense of alienation from the external world. Nabila, a devout Muslim woman, found herself wrestling with the concepts of mortality and the afterlife through the prism of her faith. Raised in a tightly-knit family where the teachings of Islam were intricately interwoven into the rhythm of daily life, Nabila always sought comfort in the belief that death was merely a transition, not an ending. “Inna lillahi wa inna ilayhi raji'un,” she would softly murmur, echoing the soothing words of the Quran that reminded her of life's ephemeral nature and the inevitability of returning to Allah.

As Nabila bore witness to the departures of cherished family members and confronted her own mortality, she drew strength from the guidance of

Islam, which offered solace and assurance in the face of death's inexorable approach. "Every soul shall taste death," she would recite, reflecting upon the Quranic verse that encapsulates the universal truth awaiting all living beings. For Nabila, death was not an entity to be feared, but a natural progression within the divine narrative, a gateway to eternal tranquility and reunion with loved ones in the hereafter.

Yet, despite her steadfast faith, Nabila wrestled with the emotional turmoil of bidding farewell to those she treasured most. As she stood vigil by the bedside of her aging parents, her heart weighed down by sorrow, Nabila found solace in the comforting belief that their souls would soon be welcomed into the loving embrace of Allah. "Insha'Allah, we will meet again in Jannah," she would whisper, her voice thick with emotion as she tenderly kissed their foreheads one last time.

In another corner of existence, Rupali, a spirited elderly woman, found herself thrust into an unfathomable struggle against the unforgiving grip of terminal cancer. "This illness will not define my essence," she declared to her family, her voice unwavering despite the tremor in her hands. As the harsh reality of her diagnosis settled in, Rupali resolutely refused to yield to despair, choosing instead to confront her adversary with unyielding determination. Amidst the relentless onslaught upon her body, she discovered solace in the small victories that marked her journey. "Each day is a precious gift," she would proclaim, a gentle smile gracing her lips as she savored life's simple pleasures with newfound appreciation. Whether it was the warm caress of sunlight on her face or the laughter of her grandchildren echoing through her home, Rupali cherished moments of joy amidst the chaotic tempest of her illness, steadfastly refusing to allow cancer to dim the beauty that still surrounded her.

As the days unfurled into weeks and the weeks morphed into months, Rupali's resolve only deepened, her determination to defy the odds burning brighter with each passing moment. "I refuse to surrender without a fight," she declared to her oncologist, her eyes blazing with a fierce determination that left no room for doubt. Even in the face of uncertainty, Rupali stood tall against the tyranny of cancer, choosing to embrace each day with unbridled passion and courage, cherishing the remarkable gift of life. Though the path ahead was fraught with tribulations, Rupali met each challenge with grace and dignity, her spirit unbroken and her resolve unwavering. "I may bear the weight of cancer, but cancer shall never possess me," she proclaimed to the world, becoming a beacon of

hope and inspiration to all fortunate enough to cross her path. For Rupali, the battle was far from over, and she would persist with every ounce of strength and determination until her final breath.

In the wake of her diagnosis, Rupali's family life assumed a renewed sense of purpose and unity. Each day became a cherished opportunity to relish moments spent with loved ones, creating indelible memories that would endure long after she departed this world. Despite the challenges and uncertainties that loomed ahead, Rupali's family remained steadfast in their devotion to one another, finding solace in the knowledge that they were navigating this arduous journey together as a formidable collective.

Meanwhile, Farhana, a devoted schoolteacher for over three decades, poured her heart and soul into nurturing young minds and shaping the future generation. Her vocation demanded long hours on her feet, engaging with students, grading papers, and orchestrating classroom activities. However, the stresses and demands of teaching, coupled with the sedentary lifestyle that often accompanied her endless hours of grading and lesson planning, gradually eroded Farhana's health. Struggling to carve out time for self-care amidst her busy schedule, she neglected exercise and proper nutrition in favor of meeting the needs of her students. Consequently, Farhana's immune system weakened, leaving her vulnerable to illness and disease. When she received the devastating diagnosis of a chronic autoimmune condition, it forced her to confront the repercussions of neglecting her own health for the sake of her career.

As she battled the overwhelming sense of hopelessness and despair that accompanied her condition, Farhana retreated from the world, seeking refuge within herself in a desperate quest for solace. "It feels as though I am trapped within a fragile bubble," she lamented, describing the profound isolation that enveloped her from friends, family, and the life she once embraced. In the stillness of the night, when the world around her rested, Farhana was consumed by haunting thoughts of mortality. She would lie awake, staring into the abyss above, grappling with the terrifying prospect of her own imminent demise. "What purpose does the struggle serve when death feels like an unavoidable fate?"

In each of these narratives, illness instigates a profound metamorphosis in perspective, eliciting feelings of separation and disconnection from the world beyond. Whether contending with chronic afflictions, terminal diseases, or the weight of mental health struggles, individuals navigating health

adversities often find themselves retreating inward as they confront the intricacies of their new realities, wrestling to rekindle their connection to a world that seems increasingly distant and foreign.

Study's Core Purpose

The primary objective of this study was to lovingly weave together the poignant narratives of individuals' lived experiences with palliative care, to delve deeply into how the delicate fabric of embodiment operates within the intricate tapestry of social contexts, and to illuminate how these rich stories could serve to enlighten those who dedicate their lives to the noble field of palliative care. The participants were brave souls undergoing palliative cancer treatment who graced the outpatient department (OPD) of a distinguished cancer institute in Kolkata.

Due to logistical considerations and the absence of a comprehensive registry of cancer patients in Kolkata, participants were thoughtfully recruited from a specialized cancer hospital, ensuring that their responses were imbued with specialized insight. The population consisted of cancer patients visiting the OPD between April and July in the year 2005. The study sought to engage individuals diagnosed with terminal illnesses who were receiving the compassionate embrace of palliative care. Initially, ten remarkable women, aged between 30 and 65, were approached; however, the fragile threads of fate wove an unexpected sorrow as one participant departed this world sooner than anticipated. All participants were afflicted with carcinoma. Data collection unfolded through qualitative research interviews, focusing on the nuanced interplay between each participant's emotions and her perception of embodiment within the palliative care environment. Each conversation culminated in tender inquiries about what they wished for their caregivers to glean from their profound experiences. Informed written consent was graciously obtained at the commencement of each interview, honoring standard ethical practices. In alignment with a phenomenological approach, the analysis unfolded in a thematic and interpretative manner. This interpretive understanding seeks to unveil how actions acquire profound significance, grounded in a heartfelt commitment to respect the lived experiences of the participants (Schwandt, 2000). The art of researching lived experience employs a phenomenological methodology that emphasizes the intimate interplay between researcher and interviewee. The noble aim of phenomenological research is to "construct

a possible interpretation of the nature of certain human experience" (Schwandt, 2000, p. 41), or to investigate experiences as they are vividly lived. Recollecting these heartfelt experiences imbues them with meaning and structure (Van Manen, 1998). Key themes identified included "The Illness Experience," which encompassed the profound emotional landscapes of embodiment and social roles, alongside the experience of "Palliative Care." This analysis was then elegantly transmuted into a meaningful description of the participants' experiences. The study endeavored to explore how the tender sense of self and identity of terminally ill patients is intricately influenced by the poignant process of bodily decline and the emotional toll of losing bodily autonomy in the face of imminent mortality.

The Dynamics of Suffering

All individuals in the study grappled with a prolonged sense of uncertainty before ultimately recognizing their impending mortality. Initially, they had to identify their ailments, often attributing early symptoms to less serious conditions. One participant remarked, "I suspected my endometriosis had returned, as I felt some discomfort." This subtle onset concealed a growing worry that could either prompt medical inquiry or lead to detrimental consequences: "Naturally, I self-diagnosed with asthma, considering my family history. I endured until I found it increasingly difficult to breathe and returned to the doctor." Next came the anxiety surrounding the diagnostic process. The participants expressed a desire for clarity about their conditions, with one stating, "Understanding what was wrong would simplify life." Their recounting of diagnosis experiences highlighted the emotional turmoil involved. One individual recounted, "The GP called me, distressed, and I insisted I was fine, entering a state of full denial. Cancer was never a possibility in my mind." Lastly, they faced ambiguity regarding treatment options and whether these would lead to a cure or merely alleviate symptoms. Participants described a sense of randomness in treatment efficacy: "After two chemotherapy sessions, we remain uncertain about the next steps. My life has diminished to a point where I no longer see the purpose in living." As the illness progressed, their bodies underwent continuous medical and personal scrutiny.

Most participants—except one—described feeling forsaken after leaving the active hospital environment, citing minimal follow-up from general practitioners. This may reflect the doctors' discomfort

with their inability to halt disease progression. Participants expressed confusion about whom to contact for health changes, stating, "After my hospital visits, we didn't know where to turn. With so many involved, it was unclear who was responsible and aware of our situation. We felt lost." Some voiced dissatisfaction with the information provided by their surgeons, contributing to their unease. They collectively agreed that a follow-up call from their GP or practice nurse after hospital discharge would have been invaluable in clarifying whom to contact and reinforcing any information that may have been inadequately absorbed.

Embodying Illness: The Intersection of Self and Disease

The concept of embodiment explores how individuals inhabit their social environments, with self-image intertwined with cultural notions of reciprocity and exchange (Turner, 2000). This study aimed to understand participants' perceptions of their dying bodies. Although societal pressures often emphasize physical appearance, the participants had shifted their focus away from looks to prioritize comfort and minimize suffering. One participant remarked on her body's deterioration, stating, "My body has deteriorated fairly markedly... in the grand scheme of things, who cares? Your body image changes."

All women respondents in the early stages of cancer often sought to normalize their illnesses, contrasting their physical appearance with those not affected by the disease. 60% of them had maintained their health through diet and exercise, and their appearances often masked their illnesses until advanced stages. One participant expressed, "I feel somewhat like a pregnant woman... People can continue to seem good until the effects of treatment, such as hair loss and the loss of limbs or breasts, identify them as having cancer." Both the disease and its treatment contributed to bodily decline. Thus, it was crucial to explore how these women experienced their bodies amid this deterioration and how they navigated their social environments. One participant noted, "There are days when I put makeup on... But now I've realized that I don't care about applying makeup if I'm not feeling good."

Using the Managing Meanings of Embodied Experiences (MMEE) framework, which examines how individuals manage their health associations, the study reveals that embodied experiences shape one's worldview and health perception. The participants faced challenges in intimacy due to the sensitivity of

nerve endings and the pain associated with physical contact. (Field-Springer, 2018) As they navigated their illness, they found themselves peeling away the layers of physical and social structure that upheld the appearance of health. While they could still think logically and retained their mental faculties, many felt as though their bodies were failing them. The process of dying raised profound fears and insecurities about their bodily integrity. The participants often described their tumors as "grotesque" and "obscene," feeling as if they were housing a "monster." One participant articulated this disconnection, saying, "It's as if my own flesh has betrayed me."

The Cartesian dualism of mind and body informed their experience, with participants often detaching their malignancies from their sense of self. The discomfort associated with their disease served as a constant reminder of their cancer. Their experiences echoed Cassell's (1991) notion of "personhood," highlighting how illness impeded their ability to fulfill social roles, especially as wives and mothers. Many women continued to manage their households as best as they could, even as their illness progressed. They mourned their inability to witness significant milestones in their children's lives, though one single woman found comfort in knowing she wouldn't leave behind a grieving family. The realities of living with a terminal illness demanded adjustments to their relationships, revealing unexpected dynamics.

A shared sense of loss permeated their narratives, including losses of creativity, friendships, family, and health. One participant lamented, "I can't accomplish the things that I thought I would be able to do." They made efforts to uphold their social responsibilities while recognizing the limits imposed by their treatments. Although they expressed joy in being around others, they also needed solitude to process their emotions. "Sometimes you just need to cry, really let it go," one stated. Ultimately, everyone experiences death uniquely, influenced by their disease progression and the perceptions of those around them. Palliative care provided the necessary tools for the participants to navigate their lives meaningfully amid their struggles.

Deterioration and Dignity: Palliative Care Experiences

Palliative care and hospice are often conflated, despite being distinct, with hospice being a specific type of palliative care for patients nearing the end of life (Kelley and Morrison 2015; Centers for Medicare and Medicaid Services [CMS] 2019; National Coalition for Hospice and Palliative Care [NCHPC] 2018). Both

approaches involve interdisciplinary teams focused on enhancing symptom management and quality of life for patients with serious illnesses and their families. The key difference lies in the timing: palliative care can begin at diagnosis and run concurrently with curative treatments throughout the illness, while hospice care is reserved for when all life-prolonging measures have been exhausted. Lawton (1998) highlights that hospices provide a space for the body to decompose away from public scrutiny, allowing patients to shield their families from witnessing their decline. Participants in the study felt they could spare their families from the emotional burden of their deterioration by entrusting their care to hospice. This transfer of responsibility to trained caregivers empowered the women, enabling them to regain control over aspects of their lives. However, as death approached, they gradually lost this sense of control and ultimately "let go."

The participants expressed satisfaction with their palliative care experience and felt supported. One woman found solace in the palliative care specialist's assurance that she could engage in activities she enjoyed, contrasting with her surgeon's advice to "go home and wait to die." Notably, none of the respondents wished for earlier access to palliative care, viewing it as something to consider later, despite feeling uncertain about the right time to contact hospice services. Nevertheless, given their level of uncertainty, early access to palliative care could have potentially benefited these women.

Conclusion

This study enriches the growing body of literature dedicated to amplifying the voices of individuals who are confronted with the profound reality of terminal illness. By interpreting these poignant narratives, we endeavor to gain deeper insights into how one's social environment intricately shapes the experience of facing death. The pervasive uncertainty that envelops the lives of these individuals is not merely a backdrop; it is a fundamental aspect of this study, framing the very essence of their existence in the twilight of life.

For the patients involved in this exploration, grappling with the relentless decline of their health and enduring the pain that often accompanies medical treatment became a profound part of their lived reality. Their experiences were imbued with emotions that fluctuated between hope and despair, as the battle against illness transformed their daily lives into a complex tapestry of struggle and resilience. The

essence of what constitutes a "happy death" often hinges on how individuals perceive themselves, how they are perceived by others and the efficacy with which medical professionals manage the intricate processes of disease and treatment.

Each person's journey towards death is uniquely their own, devoid of any universal rules governing the experience of dying. This diversity in dying reflects the rich tapestry of human emotion, where grief, acceptance, fear, and even moments of unexpected joy coexist. While this study anchors its observations within the context of hospice care, this focus does not diminish the validity of the insights gleaned; rather, it underscores the urgent need for further research in diverse community settings. By extending the scope of inquiry beyond the hospice environment, we can enrich our understanding of the myriad ways individuals confront their mortality and seek to find meaning, connection, and dignity in their final day.

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