Mother Dancing with Cancer for 17 Years: Printed Edition

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Date: 2019-02-25T00:00:00+00:00

Abstract

17 Years of Caregiving Experience and Reflection: The process of an individual with cancer contending against the disease is one of enduring suffering and contemplating the essence of life. A family' s history of battling illness constitutes a spiritual growth narrative for both patient and caregivers, representing a chronicle of acceptance and symbiosis with disease among healthcare professionals, relatives, and friends, and fundamentally, a testament to the tolerance of life and death and reverence for existence. This study systematically addresses the following dimensions: reconceptualization of cancer, family support systems for cancer patients, the hierarchical structure of oncological care, the humanistic cultivation of cancer physicians, palliative care implementation among cancer patients, and bereavement grief healing for family members.

Full Text

Preamble

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Abstract: 17 Years of Caring for My Mother with Cancer: Reflections on the Experience

The process of an individual' s struggle against cancer is a journey through suffering and contemplation of life. A family' s battle with disease constitutes a spiritual history of growth for both patient and family members, a narrative of acceptance and coexistence with illness shared by medical professionals, relatives, and friends, and ultimately, a history of tolerance toward life and death and reverence for existence. This study addresses several key themes: reconceptualizing cancer, family support systems for cancer patients, the hierarchical

nature of cancer care, the humanistic cultivation of cancer physicians, the practice of palliative care for cancer patients, and bereavement grief counseling for family members.

During the 17 years of my mother' s illness, I held a unique identity: that of a cancer patient' s family caregiver. Throughout her illness, I felt our family was both the most unfortunate and the most fortunate. My mother lived with bronchiectasis for 20 years and chronic pulmonary heart disease for 2 years. In 2001, she underwent radical surgery for esophageal cancer; in 2007, she had surgery for intestinal obstruction. She suffered from chronic reflux esophagitis and, in 2016, received a pacemaker implantation for bradycardia. She had experienced lower limb edema for three years, which worsened in her final month. After her passing on December 30, 2017, I often regretted not having cherished our time together more deeply, wishing I could hold her once more and spend more time with her. In retrospect, those hospital stays with my mother now seem a form of beauty and happiness.

My reflections on 17 years of caring for my mother are as follows:

First, cancer diagnosis and treatment provide an opportunity for philosophical reflection on life. Cancer is a misfortune, yet it is also a "stroke of luck" in that it grants patients and families time for psychological preparation and to mobilize family strength—it becomes a war in which the entire family participates. In this era of coexistence with cancer, diagnosis becomes an occasion for contemplating life' s meaning. Cancer is an endogenous disease [?]. It represents a profound journey of entrusting one' s life, a soul-stirring expedition [?]. At the Second Medical Humanities Conference, Teacher Wang Yifang shared a curated list of cancer literature, including foreign works such as *The Cancer Ward*, *Grace and Grit: Spirituality and Healing in the Life and Death of Treya Killam Wilber*, *When Breath Becomes Air*, *Everyone' s War*, *Chasing Daylight*, *The End of Your Life Book Club*, *The Card for Brianna*, *The Shadowless Lamp*, *Oscar and the Lady in Pink*, and *Illness as Metaphor*. These texts help readers contemplate life and explore existential questions. The three-year survival rate for esophageal cancer is 44.5% [?]. I am grateful that life granted my family and me seventeen years of living with cancer alongside my mother, sharing the experience of reading life' s meaning together.

Second, a cancer patient' s social support system is as vital as medication. A TED talk referenced a 75-year longitudinal study from Harvard University revealing that the key factors influencing longevity, happiness, and health are not wealth or status, but the quality of an individual' s relationships with family, friends, and community. Good interpersonal relationships benefit both body and mind. My mother lived within a family and community rich in affection; the care from family, visits from relatives, and assistance from neighbors were the sources of her strength in living with cancer. Just as Balint groups advocate that "the doctor is the drug," in the battle against cancer, family members are equally potent medicine.

Third, the focus of cancer medical care should be in the community. Minor illnesses should be treated in community settings, major illnesses in hospitals. Over 17 years, my mother was treated at five tertiary hospitals and one community hospital. She developed a profound, decades-long relationship of trust with Dr. Chen at the community hospital. In 2016, when my mother was in unbearable pain, she asked Dr. Chen for sleeping pills. After much hesitation, he finally agreed. Since sedatives can be fatal for respiratory patients, Dr. Chen' s decision was technically inappropriate. Yet rather than blaming him, our family felt deep respect. When the tertiary hospital' s attending physician criticized this as medical misconduct, my mother offered a simple statement: "I insisted on using sleeping pills for pain relief. If anything happens, it' s not the doctor' s fault." As a family member, I suddenly understood the deeper meaning of the "doctor-patient community." Current policies promoting the 下沉 of health resources and family doctor contract systems further facilitate the formation of community-based doctor-patient partnerships.

Fourth, the humanistic cultivation of cancer physicians is a blessing for patients. Hospitals serve as spaces for redeeming and caring for both body and soul. Physicians must be clinical, not "away from the bedside" —a doctor who abandons the bedside is not a good doctor. What we provide patients is sometimes technology, sometimes management, sometimes medicine, but fundamentally should be care [**?**]. My mother deeply trusted a respiratory physician at a tertiary hospital; in her view, this doctor was an authority who could cure all her discomforts. This excellent trust relationship enhanced her compliance throughout her cancer journey. Ultimately, this most trusted physician attended her funeral, insisting on accompanying his patient on her final journey. This may be the most beautiful doctor-patient relationship in the world.

In May 2016, I experienced my first family resuscitation. During 14 days in the respiratory ICU caring for my mother, I witnessed the passing of an elderly woman who had suffered from pulmonary fibrosis for many years. Her children were abroad; throughout her hospitalization, she was cared for by her niece and husband. The elderly woman arrived gasping for breath, her face gradually paling, her moans growing weaker until her breathing ceased. That night, I—as a fellow patient' s family member, not her relative—quietly wept. I wondered whether her children abroad could feel the desolation of that life passing. I watched as medical staff in dark green surgical gowns slowly covered the deceased' s body and collectively saluted her. To this day, the image of those healthcare workers solemnly paying respects to the deceased frequently appears before my eyes. I even feel that the elderly woman' s distant children owe those physicians a debt of gratitude.

The ancient physician Sun Simiao said: "The superior physician heals the nation, the middling physician heals the person, the inferior physician heals the disease." Paul Tournier, a pioneer advocating for whole-person, comprehensive medical care, believed that a physician' s duty is to share suffering with patients and accompany them [**?**]. While treating illness, doctors are also healing a sick society.

Fifth, the construction and practice of palliative care culture remains a formidable task. My mother was first admitted to a local tertiary hospital for emergency treatment and discharged with a diagnosis of “acute exacerbation of chronic obstructive pulmonary disease, chronic pulmonary heart disease, first-degree atrioventricular block, incomplete right bundle branch block, pulmonary bullae, hypoproteinemia, mild anemia, cardiac function class III, type II respiratory failure—improved after mechanical ventilation.” For the subsequent 19 months, she used non-invasive ventilator and home oxygen therapy 4-6 hours daily, later experiencing adverse reactions including dry, hardened tongue, hearing damage, and lower abdominal bloating. She also received a pacemaker for bradycardia. I sometimes wonder: if there had been another chance for intervention, would I still have chosen ventilator and tracheostomy treatment for my mother? In the end, she lost the opportunity for resuscitation en route to the hospital and passed away peacefully in the emergency room. Coming from a medical family, I more readily accept palliative care principles, yet when faced with making decisions for my own mother, my heart struggled.

Since 2016, the Geriatrics Department of Peking Union Medical College Hospital, the Palliative Care Branch of the Chinese Geriatrics Health Care Research Association, the Nursing Department of Peking Union Medical College Hospital, and the Beijing Living Will Promotion Association have organized three training sessions for directors of geriatric palliative care. These programs addressed symptom management for severe and terminal patients, comfort care, communication with patients and families, psychological and spiritual care, home-based palliative care, volunteer management, patient autonomy rights, ethical considerations in medical decision-making, symptom control, breaking bad news, art therapy, staff burnout and self-care, and bereavement companionship. The development of palliative care in China remains a long-term endeavor.

Sixth, bereavement grief counseling for cancer patients’ families urgently needs implementation. The darkest days of my life were escorting my mother’ s body to the funeral home in the cold winter. Bidding farewell to the mother who gave me life brought successive waves of negative emotions: reluctance, self-blame, grief, and mild depression. In the year following her death, every holiday seemed to inflict fresh wounds. Bereavement sends shockwaves through the entire family. Yet death is life’ s greatest teacher—it grants the bereaved courage to reaccept themselves and life, to feel gratitude, and gives us opportunity to reexamine existence. One day after my mother’ s passing, I received a follow-up call from the hospital. On my end of the line, I felt deeply moved and warmed. Telephone follow-up represents a compassionate extension of medical services. Mayo Clinic has established a complete service chain of “appointment—reception—guidance—treatment—follow-up” [**?**]. Mayo Clinic’s Chinese website embeds 23 patient stories, demonstrating how medicine, education, and research collaboratively focus on patient care and highlighting Mayo’ s cultural soft power. Humanism means respecting human life, dignity, emotion, and value [?].

Bereavement events severely impact survivors' psychology, physiology, emotions, cognition, and daily life, increasing risks for psychosomatic illness. Some bereaved individuals experience prolonged grief disorder and complicated grief. In the dark passage of bereavement, survivors need profound companionship from medical professionals and society, urgently requiring bereavement grief counseling.

Over the past 30 years, bereavement grief has received sustained attention in the West, forming core research teams [?]. In China, bereavement grief counseling for cancer patients' families has begun attracting academic attention. Individual cancer battles and bereavement grief are not merely family matters but social events. Cancer patient caregivers urgently need social services including psychosocial interventions [?]. Bereavement counseling requires broader interdisciplinary participation and wider societal engagement, promoting death education, managing anticipatory grief, guiding family members in bidding farewell at end-of-life, and helping them navigate grief post-bereavement. Importantly, families, communities, hospitals, and society must form alliances with cancer patients' families to promptly restore psychological order and reconstruct meaning in life after bereavement. Hospitals need risk assessment for cancer patient mortality; early awareness of approaching death allows families to make arrangements without regret, and anticipatory grief can mitigate the intensity of post-bereavement sorrow.

Conclusion

Medical development has integrated seven elements: shamanic healing, religion, science, technology, psychology, humanities, and philosophy, requiring humanity to reconcile with nature, with itself, and with the soul [?]. The eastward spread of Western medicine has gradually Europeanized Chinese medical technology, yet humanistic care within the Chinese context has not kept pace. Medicine is humanity' s Tower of Babel in pursuit of health; technology and drugs alone cannot solve all cancer and cancer pain problems. For a long time, Chinese people have received insufficient death education, have low awareness of living wills, and lack access to hospice facilities, palliative care wards in general hospitals, community hospice wards, and home-based hospice services. Research on bereavement counseling and healing for grieving families remains limited. China' s death culture framework needs to incorporate diverse perspectives from philosophy, psychology, medicine, literature, and art; integrate multiple therapeutic approaches including bibliotherapy, music therapy, letter therapy, cognitive-behavioral therapy, film therapy, philosophical therapy, narrative therapy, art therapy, and horticultural therapy; continuously improve humanistic healing in scientific and technological society; achieve reconciliation between science/technology and humanities, integration between instrumental rationality and value rationality; gradually construct a palliative care culture suited to China' s national conditions; promote palliative care practice; and strengthen the bereavement grief counseling system for families.

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