Journal of Clinical and Nursing Research, 2025, Volume 9, Issue 11
http://ojs.bbwpublisher.com/index.php/JCNR
Online ISSN: 2208-3693
Print ISSN: 2208-3685

End-of-Life Care: A Case Study on Palliative Care Practice for a Child with Pineal Tumor

Hui Ma[1], Minxuan Shi[2], Yuanyuan Tong[3], Huiping Wang[4], Yang Liu[5]*

[1]School of Sociology and Anthropology, Xiamen University, Xiamen 361005, Fujian, China
[2]School of Public Administration, Hohai University, Nanjing 210024, Jiangsu, China
[3]School of Foreign Languages, Zhongbei College, Nanjing Normal University, Danyang 212300, Jiangsu, China
[4]School of Sociology and Anthropology, Xiamen University, Xiamen 361005, Fujian, China
[5]Quanzhou Vocational and Technical University, Quanzhou 362268, Fujian, China

**Corresponding author: Yang* Liu, 756915639@qq.com

Abstract: Palliative care extends beyond the individual child to encompass their family, healthcare providers, and broader socio-emotional networks. Timely and analytically informed palliative interventions not only alleviate the emotional burden experienced by terminally ill children and their family caregivers due to prolonged caregiving but also enhance the quality of life in the child's final stages. Currently, it is particularly important to note that an overemphasis on the healing function of physical spaces may risk relegating humanistic care to the margins once again. Therefore, when accompanying children through their end-of-life journey, it is essential to fully respect their need to express memories, maintain autonomy, and preserve dignity. They should be gently "seen" and compassionately accompanied until the very end, thereby facilitating a meaningful farewell that embodies a form of spiritual ecology.

Keywords: Pediatric palliative care; Personalized care; Quality of life

---

1. Introduction

With the advancement of medical technology, a paradigm shift from curative treatment to palliative care has gradually taken place. While the lives of many critically ill children have been prolonged, for those with incurable diseases and their families, the question of how to face the end of life with dignity has become a serious challenge. Under the traditional disease-centered medical model, excessive treatment at the end of life not only exacerbates the physical and psychological suffering of the child but also places a heavy emotional and financial burden on the family. In this context, pediatric palliative care has emerged, marking a transition from a "disease-focused" curative approach to a "person- and family-centered" model of holistic care. The goal is no longer merely to prolong life, but to enhance the quality of the child's remaining days, allowing them to pass away free from pain and with dignity, while supporting the family through the grieving process.

2. Literature review

Research on palliative care has long been a growing focus in academia. The concept of palliative care can be traced back to late 19th-century Europe, particularly the United Kingdom. In 1967, St. Christopher's Hospice, founded by Cicely Saunders in the UK, marked the beginning of the modern palliative care movement [1]. The modern concept of palliative care, shaped in the 20th century, emphasizes the right of choice, respecting children's decisions and providing comprehensive care addressing physical, psychological, spiritual, and emotional needs. Initially developed for children with advanced cancer, palliative care later extended to all children experiencing severe pain and suffering [2]. Since the 1960s, palliative care has rapidly expanded in Western countries and gradually spread worldwide. Different countries and regions have developed distinct models. For instance, Germany and Japan have established relatively mature systems supported by health insurance funds. In the U.S., Elisabeth Kübler-Ross further popularized the idea through her influential book On Death and Dying [3]. In China, palliative care emerged in the 1980s but has developed relatively slowly, influenced by traditional cultural values and the general level of public awareness [4]. Over the past decades, Chinese palliative care services have mainly focused on adults and the elderly, while pediatric palliative care has received insufficient attention [5]. Meanwhile, academic discussions in China have often centered on physical settings, such as inadequate qualifications of medical facilities and communities for palliative care, with insufficient attention to children's subjectivity at the end of life [6]. Internationally, however, pediatric palliative care has been widely discussed, with consensus around interdisciplinary collaboration and respect for children's agency and decision-making. For instance, the American Academy of Pediatrics (AAP) emphasized in its 2019 guidelines the importance of children's active participation and multidisciplinary teamwork [7]. Scholars have also highlighted the role of children's spirituality and emotions in shaping their perception of death, an essential part of their agency in palliative contexts [8]. International standards further underscore the importance of addressing children's developmental and social needs, alongside their families' quality of life [9]. Current research has also expanded into issues such as the timing of interventions, family-centered models, and more [10,11]. In this process, children, as individuals with volition, purpose, and self-awareness, can actively engage in information exchange with the external world [12]. Palliative care brings comfort by affirming life. Its goal is to support dignity and quality of life for the individual, regardless of the setting [13]. In South Africa, palliative care is needed by an average of 1 in 60 people, with the demand among child patients being even higher [14]. According to research by the international scholar Julia, approximately 21.6 million children and their families worldwide currently require palliative care services. This figure underscores the significant scale of pediatric palliative care needs and highlights the urgent attention required for its development [15].

At the international level, there is a substantial body of visualized research on pediatric palliative care, which has already incorporated attention to tiered care models within palliative services. Focusing on the domestic context, pediatric palliative care in China remains in its initial stages of development, facing multiple structural challenges that are primarily manifested as three major disconnects.

Firstly, a disconnect in service provision. Service resources are highly scarce, and the content of care is singular. Second, a disconnect in medical paradigms. The mainstream medical culture in China remains deeply rooted in the traditional paradigm of "prolonging life at all costs". For terminally ill children, excessive medical interventions are common. This not only fails to improve the quality of life at the end-of-life stage but may instead increase suffering and lead to a waste of medical resources. The decision to transition from a "curative" to a “palliative” approach, lacking support from socio-cultural and ethical frameworks, often places heavy moral pressure on both healthcare professionals and families. Third, a disconnect in cultural ethics. This is the most distinctive local challenge. Domestic literature frequently discusses the profound impact of the “taboo surrounding death” and the culture of “filial piety” on the promotion of palliative care. On one hand, adult society generally avoids discussing death with children, leading to the inadvertent denial of children’s right to information and participation. On the other hand, the culture of “filial piety” drives families to spare no effort to prolong their child’s life, making the decision to transition to palliative care exceptionally difficult. In particular, Western-style “spiritual care”, such as chaplaincy services is difficult to directly transplant into a Chinese society lacking a strong religious tradition. How to construct a localized spiritual support system based on ethical and moral foundations is an area requiring further in-depth research in the future.

3. Case data

3.1. General materials

The patient is a 9-year-old girl in the fourth grade of elementary school. She has been undergoing continuous treatment for recurrent metastatic mixed germ cell tumor of the pineal gland, which was later managed by the hematology department. She has now been transferred to the palliative care unit but still requires necessary pain management. Upon admission, she had been experiencing a persistent fever for nearly half a month, with poor response to antipyretic measures. She also presents with body aches, difficulty breathing requiring hyperbaric oxygen assistance, and has undergone two emergency resuscitations recently. Her overall condition is weak, and she remains drowsy most of the time. The patient is the only child of divorced parents, and her mother has been the primary caregiver during her illness. Her Activities of Daily Living (ADL) score is 41, which primarily assesses an individual’s independence in basic daily activities such as eating, dressing, and toileting. A lower score indicates a higher degree of dependence on others for care.

3.2. Key issues and needs assessment

In this case, the management of the child’s condition and symptoms are of paramount importance. Due to the complexity of her condition following tumor recurrence and metastasis, she experiences significant pain and respiratory distress. Throughout this process, the medical team’s primary focus is on enhancing palliative symptom control. Secondly, the child has psychosocial needs. During periods of consciousness, she has expressed to her mother a wish to have video recordings of her hospital treatment preserved, wanting to leave behind her own unique story. Finally, it is necessary to provide grief support for the child’s family (particularly the mother) and connect them with appropriate funeral resources.

3.3. Intervention and support process

Firstly, professional medical care and symptom control form the cornerstone of palliative care, primarily led by the medical team. The goal is not only to alleviate the child’s physical pain through standardized procedures and medication but also encompasses crucial “implicit care”. This includes establishing a solid doctor-patient trust relationship, providing emotional comfort during pain episodes, and addressing negative emotions arising from treatment discomfort, ensuring the child receives dual (soothing/support) both physically and psychologically.

Secondly, personalized comprehensive support services are provided. When the condition is stable, medical social workers collaborate with the team to offer diversified professional support to the child and their family. The services mainly cover two areas: Non-pharmacological adjuvant therapies: To reduce weakness and pain caused by chemotherapy, social workers actively connect resources, such as arranging professional massage therapists and integrating gentle therapies from the Traditional Chinese Medicine department including applying moxibustion patches and auricular acupressure seeds. An inflatable leg massage device is also used to enhance comfort non-pharmacologically and address potential pressure injuries from prolonged bed rest; Social resource linkage such as assistance is provided to the family in applying for social charity aid to alleviate the mother's financial pressure. This included successfully securing assistance funds for children with critical illnesses like leukemia and initiating online fundraising campaigns such as "Waterdrop Fundraising".

Thirdly, the focus of daily care prioritizes both safety and comfort, particularly regarding hygiene. "Repositioning" and "bathing" are key aspects directly impacting the child's quality of life and dignity. These must adhere to the principles of safety first and individualization. The decision to bathe the child requires strict assessment by the medical team. For children deemed physically able, environmental temperature, water temperature, and duration must be strictly controlled. For the child in this case with a pineal gland tumor, who was weak, had multiple tubes, and a high infection risk, sponge baths or localized cleaning were adopted to avoid physical exhaustion and infection. Post-bathing skin care also received extra attention to prevent complications.

Given that the child in this case expressed a strong desire for emotional expression when conscious, the medical social worker employed the "Photovoice" method to create a "time capsule storybook" for the family, documenting the child's treatment journey in the hospital. This enhanced emotional interaction and shared life experiences among family members. Medically, pain was managed with opioid medications per medical orders, complemented by non-pharmacological interventions like aromatherapy and horticultural therapy. These measures effectively alleviated the child's physical suffering, enhanced her comfort and sense of dignity at the end of life, and ultimately contributed to a peaceful and dignified passing, further enriching the understanding of safeguarding children's right to life. The practice also revealed the child's unmet need for religious services at the end of life.

Currently, within China's system, it is challenging for medical social workers to coordinate and provide such support systematically. In contrast, palliative care systems in Western countries often integrate religious services such as chaplaincy care as routine component. Through themes like spiritual solace and exploring life's meaning, they effectively alleviate the fear of death for both the child and family, enhancing spiritual comfort. In mainstream Chinese culture, rooted in ethical morals and influenced by death taboos and filial piety culture, families often tend to prioritize life-prolonging treatments. Religious support is often regarded as a private matter, making it difficult to integrate systematically into the service framework. This difference suggests the need to explore spiritual care pathways more suited to the local cultural context within China (**Figure 1**).

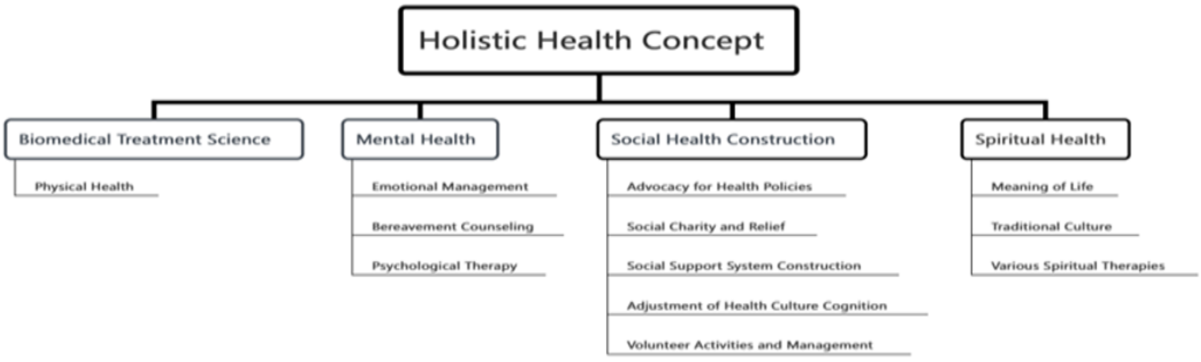

Figure 1. The holistic view of health.

4. Reflections on social work interventions in pediatric palliative care

4.1. A multidisciplinary collaborative model for pediatric palliative care

In China, palliative care services currently primarily target the elderly end-of-life population, while practices in the pediatric field are still in the exploratory stage. Compared with the elderly, the end-of-life situation of a child inflicts a more intense emotional impact on the family, who often endure deeper suffering and greater psychological stress that is harder to adjust to. Against this backdrop, constructing an interdisciplinary professional service system is particularly crucial, as its quality directly affects the quality of life and dignity in death for both the child and their family during the end-of-life stage.

After children enter the palliative care phase, they often continue to endure physical and mental suffering due to the disease itself and the side effects of previous treatments, necessitating comfort-oriented comprehensive medical interventions. Simultaneously, the families of these children commonly face multiple challenges, including financial pressure, caregiving burden, and spiritual grief. Therefore, it is imperative to establish a multi-professional collaborative mechanism involving medical social workers, physicians, psychological counselors, family therapists, and physiotherapists, all working as equal partners. Through a systematic and integrated service model, this team can collectively address the holistic needs of both the child and the family.

4.2. The shaping effect of modern life education on the public's view of death

In traditional Chinese society, constrained by the overall quality of life, there was a prevalent tendency to "prioritize lifespan length over life quality", which largely hindered the promotion of paid palliative care services. However, with the rapid socio-economic development over the past four decades, public attention to life quality has significantly increased, and the practical need for life education has become increasingly prominent. Against this backdrop, developing localized life education based on China's moral and cultural traditions can help guide the public toward forming a more positive and healthy understanding of death and values of life. This is not only of profound significance for the quality of individual end-of-life care but also serves as an important pathway for promoting social civilization progress and the enhancement of life quality.

4.3. The constraining effect of missing service standards on palliative care professionalization

In countries with more mature palliative care systems, such as the United Kingdom and the United States, service quality is safeguarded by highly detailed, proceduralized, and legalized standard frameworks. These standards not only clarify the scope of responsibilities and collaboration mechanisms for various professionals but are also supported by legislative measures. In contrast, palliative care in China is still in its early stages of development. The number of service institutions remains limited, relevant regulations lag, and there is a lack of unified norms regarding service content and procedures. Public understanding often remains at the level of humanitarian care, with limited recognition of its role as a professional service capable of enhancing quality of life, integrating multidisciplinary resources, and systematically addressing end-of-life issues. Therefore, accelerating the establishment of palliative care service standards and policy frameworks tailored to national conditions is crucial for promoting the professional development of this field.

5. Comprehensive reflections on the medical social worker's intervention process in pediatric palliative care

5.1. The localization ethical dilemmas in pediatric palliative care

The ethical core of palliative care is to ensure that children at the end of life receive holistic care, physically, psychologically, socially, spiritually and able to die with dignity. However, these professional ideal faces severe practical challenges within the Chinese context.

Firstly, professional service capacity is weak. The scale of development and resource support for medical social workers remain insufficient, resulting in heavy reliance on government-funded programs or out-of-pocket payments by families, which limits accessibility. Secondly, a more fundamental conflict arises from differences in medical paradigms. The mainstream healthcare system still adheres to a traditional model focused on "cure", often resorting to excessive pharmacological and instrumental interventions for terminally ill children. This not only diminishes their quality of life at the end-of-life stage but also leads to a waste of medical resources.

Yet, the decision to abandon "curative" efforts in favor of "palliative" care, lacking support from traditional ethics, often places caregivers under significant moral pressure, forming a core obstacle to the wider adoption of palliative care.

5.2. The particularities of the child as a subject and the ensuing challenges

The Children, as service recipients, possess a high degree of uniqueness, necessitating adherence to their cognitive developmental patterns. Physiologically, children's expression of pain and emotion differs significantly from that of adults, with younger children particularly requiring parental assistance in developing individualized care plans. Psychologically, their immature cognitive capacities make it difficult for them to comprehend the abstract concept of death, often leading to fear. According to Piaget's theory of cognitive development, a child's understanding of death is concrete. Therefore, discussions about death must employ language and methods appropriate to their age and cognitive level, focusing on alleviating fear rather than imparting abstract concepts.

This raises a critical ethical issue: to what extent should children have the right to know about their own condition and to participate in decisions regarding their treatment? In practice, this right is often exercised entirely by guardians. Furthermore, influenced by the cultural "taboo of death", adults generally avoid discussing death with children. Consequently, the fundamental principle that "the child is an independent individual with unique needs" is difficult to genuinely implement within current pediatric palliative care services.

5.3. Barriers to transitioning from isolated care to integrated services

The ideal model of palliative care should be a multi-disciplinary, integrated service system encompassing medical, psychological, social, legal, and even spiritual support. Developed countries have achieved this through institutionalized team-building. In contrast, the service content in China remains relatively singular, primarily focusing on psychological comfort and daily living care, with systemic barriers hindering multi-sectoral collaboration.

A typical case is the absence of spiritual care. The family involved in this study had a need for religious services, which was difficult to meet under the current system. In the West, services such as chaplaincy are standard components, effectively providing solace. Chinese society, however, is rooted in an ethical and moral cultural foundation, where approaches to end-of-life issues are deeply influenced by "filial piety culture". This culture favors prolonging life at all costs, resulting in religious or spiritual support being regarded as a private matter, difficult to integrate into the public service system. This reflects a structural shortcoming in the localization process of the holistic care concept.

5.4. Integrating inverted care with intelligent humanity

"Reverse Hospice Care" refers to the phenomenon where terminally ill children express gratitude and well-wishes to their caregivers. This emotional feedback can sometimes create an illusion of "improved condition" for the caregivers. It is crucial to recognize that this constitutes a positive emotional response from the child, reflecting their capacity for empathy and connection towards the caregivers' efforts, rather than indicating an actual turnaround in their medical prognosis. Building on this understanding, future service systems should not only maintain routine pain management and grief counseling but also strengthen focus on fundamental care aspects such as nutritional support and bowel care.

A more forward-looking pathway lies in the deep integration of technology and humanistic care. While artificial intelligence (AI) has demonstrated value in adult palliative care including symptom prediction, its application in pediatrics faces unique ethical threshold challenges, such as the legitimacy of surrogate decision-making and the risks associated with emotional substitution. Future research, grounded in the holistic health perspective and complex adaptive systems theory, could explore the development of intelligent palliative intervention systems tailored to children's developmental characteristics. This approach aims to address the "precision dilemma" and "humanistic crisis" currently faced by pediatric end-of-life care, potentially paving the way for paradigm innovation in China's child-focused hospice services.

6. Conclusion

Pediatric palliative care represents a crucial shift from curative-focused treatment to holistic, dignity-centered support for children with life-limiting illnesses and their families. This case study highlights the urgent need in China to develop a culturally sensitive, multi-disciplinary service model that integrates medical, psychosocial, and spiritual support while respecting the child's autonomy and emotional needs. Moving forward, it is essential to establish standardized practices, enhance professional training, and foster public awareness to ensure that every child can experience a peaceful and meaningful end-of-life journey.

Disclosure statement

The authors declare no conflict of interest.

References

[1] Cecconello L, Erbs E, Geisler L, 2022, Ethical Conducts and the Care of Terminal Patients. Revista Bioética, 30: 405–412.

[2] Silva E, Sudigursky D, 2008, Conceptions About Palliative Care: Literature Review. Acta Paulista de Enfermagem, 21: 504–508.

[3] van Oorschot B, Ishii K, Kusomoto Y, et al., 2020, Anxiety, Depression and Psychosocial Needs Are the Most Frequent Concerns Reported by Patients: Preliminary Results of a Comparative Explorative Analysis of Two Hospital-Based Palliative Care Teams in Germany and Japan. Journal of Neural Transmission, 127(11): 1481–1489.

[4] Zheng J, 2009, The Ethical Dilemma and Construction of Localized Palliative Care in China. Journal of Nanjing Medical University (Social Sciences Edition).

[5] Ji Q, Lu Y, Li Y, et al., 2017, Exploratory Research on the Social Work Practice System of Localized Pediatric Palliative Care in China. Journal of Chongqing Technology and Business University (Social Sciences Edition).

[6] Contro N, Larson J, Scofield S, et al., 2002, Family Perspectives on the Quality of Pediatric Palliative Care. Archives of Pediatrics & Adolescent Medicine, 156(1): 14–19.

[7] Feudtner C, Friebert S, Jewell J, et al., 2013, Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations. Pediatrics, 132(5): 966–972.

[8] Himelstein B, Hilden J, Boldt A, et al., 2004, Pediatric Palliative Care. New England Journal of Medicine, 350(17): 1752–1762.

[9] Benini F, Papadatou D, Bernadá M, et al., 2022, International Standards for Pediatric Palliative Care: From IMPaCCT to GO-PPaCS. Journal of Pain and Symptom Management, 63(5): e529–e543.

[10] Cheng B, Rost M, De Clercq E, et al., 2019, Palliative Care Initiation in Pediatric Oncology Patients: A Systematic Review. Cancer Medicine, 8(1): 3–12.

[11] Hammer N, Bidstrup P, Brok J, et al., 2023, Home-Base Specialized Pediatric Palliative Care: A Systematic Review and Meta-Analysis. Journal of Pain and Symptom Management, 65(4): e353–e368.

[12] Fu Y, Zhang Z, 1997, The Theory of the "Lifeworld": Habermas Critique and Reconstruction. Journal of Shandong University (Philosophy and Social Sciences), 4: 8–13.

[13] Kedanis R, 2016, The Miracle of Henry the Hospice Cat. Holistic Nursing Practice, 30(6): 379–381.

[14] Khumalo T, Maasdorp V, 2016, The Island Hospice Model of Palliative Care. Ecancermedical Science, 10(654): 1–7.

[15] Downing J, Boucher S, Daniels A, et al., 2018, Paediatric Palliative Care in Resource-Poor Countries. Children (Basel), 5(2): 1–12.