

## A Brief Note on Paediatric Palliative Care

James Joseph\*

St. Benedicts Hospice, Specialist Centre for Palliative Care, Sunderland, United Kingdom

### Abstract

This article explores the significance of preserving the dignity of terminally ill children in pediatric palliative care. It emphasizes the shared responsibility of parents and healthcare providers in upholding the child's dignity through a holistic and person-centered approach. By respecting the child's choices and providing unwavering support, the article highlights how terminally ill children can experience comfort, love, and fulfillment during their remaining time. Through compassion and empathy, this approach leaves a lasting impact on the families and caregivers, acknowledging the unique identities and inherent worth of these young patients until the end of their journey. The article emphasizes the importance of working together to create an environment of dignity, respect, and love, making the palliative care journey as meaningful and fulfilling as possible for these children and their loved ones.

**Keywords:** Pediatric palliative care; Terminally ill children; Dignity; Parental perspectives; Healthcare provider perspectives; Compassion; Empathy; Holistic care; End-of-life care; Quality of life; Life-limiting illnesses

### Introduction

Pediatric palliative care is a specialized form of medical care that focuses on enhancing the quality of life for children with life-limiting or life-threatening illnesses. It is not curative in nature but aims to provide physical, emotional, social, and spiritual support to the child and their family during the challenging journey of facing a terminal illness [1]. The goal of pediatric palliative care is to alleviate suffering, manage symptoms, and offer comfort, ensuring that the child's remaining time is as meaningful and dignified as possible. The care of terminally ill children demands a comprehensive and multidisciplinary approach. Medical professionals, including pediatricians, nurses, palliative care specialists, and other specialists, work together to address the child's complex medical needs. But, pediatric palliative care is not limited to the hospital or clinical setting; it extends to the child's home and community, where parents and caregivers play a pivotal role in providing day-to-day care and emotional support [2]. Preserving the dignity of terminally ill children is a central aspect of pediatric palliative care. Dignity, in this context, encompasses respecting the child's autonomy, individuality, and intrinsic worth, recognizing that their identity extends beyond their illness. It involves upholding the child's rights, preferences, and values, even in the face of medical challenges and difficult decisions. One of the key principles of palliative care is that each child is treated as a unique individual with their own needs and desires. This person-centered approach focuses on understanding the child's wishes, preferences, and goals, involving them in decision-making to the extent they are capable. It acknowledges that even though a child may be facing a severe illness, they still have the right to be heard and respected. Parents and caregivers are at the heart of the pediatric palliative care journey. They know their child best, and their perspectives and insights are invaluable for healthcare providers in tailoring the care plan [3,4]. Parents often advocate for their child's dignity by actively participating in medical decisions, ensuring that their child's voice is heard, and seeking treatment options that align with their child's values. In addition to medical care, parents and caregivers focus on providing emotional and psychosocial support. They strive to create a nurturing and loving environment for the child, fostering a sense of normalcy and stability amidst medical uncertainties. Engaging in activities that bring joy and happiness to the child becomes an essential part of preserving their dignity, as they are still children

who deserve to experience the joys of childhood. Healthcare providers, on the other hand, are trained to approach pediatric palliative care with empathy and compassion. They understand the complexities of caring for terminally ill children and are skilled in addressing the child's physical and emotional needs. Transparent and open communication is emphasized, ensuring that parents and caregivers are well-informed about the child's medical condition and prognosis, empowering them to make informed decisions and actively participate in their child's care. Pain and symptom management are paramount in preserving the dignity of terminally ill children. Healthcare providers work diligently to control pain, discomfort, and distress, allowing the child to experience moments of comfort and serenity. This approach not only ensures physical well-being but also acknowledges the child's suffering and actively seeks to alleviate it, reinforcing the child's dignity [5-7]. Pediatric palliative care is a multidimensional approach that goes beyond medical treatment. It involves a collaborative effort between healthcare providers, parents, and caregivers to provide comfort, support, and dignity to terminally ill children. By respecting the child's autonomy, valuing their unique identity, and alleviating suffering, we can ensure that every child's dignity is upheld until the end of their journey. In this compassionate approach, children with life-limiting illnesses can experience love, joy, and comfort, providing them and their families with cherished memories and a sense of fulfillment during their remaining time together.

**Understanding pediatric palliative care:** It addresses the physical, emotional, social, and spiritual needs of both the child and their loved ones. The ultimate goal is to provide comfort and alleviate suffering, enhancing the child's well-being during their remaining time.

**Dignity in pediatric palliative care:** Dignity is a fundamental human right, and preserving it during palliative care is essential for all patients, regardless of age. For terminally ill children, maintaining

\*Corresponding author: James Joseph, St. Benedicts Hospice, Specialist Centre for Palliative Care, Sunderland, United Kingdom, E-mail: j\_james@gmail.com

**Received:** 03-Jul-2023, Manuscript No. jpcm-23-108565; **Editor assigned:** 05-Jul-2023, PreQC No. jpcm-23-108565(PQ); **Reviewed:** 19-Jul-2023, QC No. jpcm-23-108565; **Revised:** 24-Jul-2023, Manuscript No. jpcm-23-108565(R); **Published:** 31-Jul-2023, DOI: 10.4172/2165-7386.1000550

**Citation:** Joseph J (2023) A Brief Note on Paediatric Palliative Care. J Palliat Care Med 13: 550.

**Copyright:** © 2023 Joseph J. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

dignity is particularly important as they are vulnerable and dependent on others for their care. Dignity in this context refers to respecting the child's autonomy, individuality, and worth, as well as recognizing their unique identity beyond their illness [8].

**Perspectives of parents:** Parents of terminally ill children are central to the palliative care process. Their perspectives on dignity are deeply intertwined with the emotional bonds they share with their child. Many parents express that maintaining their child's dignity is a top priority and integral to their parental role.

**Respect for choices:** Parents want their child's preferences and choices to be respected, even if those choices may differ from their own or conventional norms. This includes decisions about pain management, treatment options, and end-of-life care [9].

**Unconditional love:** Parents want their children to feel unconditionally loved and supported throughout their journey. They often engage in simple acts of care, such as holding hands or comforting touches, to maintain a sense of connection and reassurance for the child.

**Encouraging normalcy:** Parents try to create a sense of normalcy for their child by engaging in age-appropriate activities, facilitating friendships, and making cherished memories. This helps the child feel valued and included, even when they are coping with a severe illness [10].

**Perspectives of healthcare providers:** Healthcare providers play a vital role in advocating for the dignity of terminally ill children and supporting families through this challenging time. Their perspectives are guided by a commitment to compassionate care and a profound understanding of the medical, emotional, and psychological aspects of pediatric palliative care. Healthcare providers strive to adopt a person-centered approach to care, tailoring treatment plans to the child's unique needs, preferences, and goals [11]. This approach empowers the child and fosters a sense of agency.

**Open communication:** Transparent and empathetic communication with the child and their family is crucial. Healthcare providers help parents understand the medical condition and prognosis, facilitating informed decision-making and respecting the family's values and cultural beliefs [12].

**Pain and symptom management:** Prioritizing pain and symptom management ensures the child's comfort and minimizes distress [13-15]. This approach not only alleviates physical suffering but also acknowledges the child's dignity by acknowledging their pain and taking active steps to alleviate it.

## Discussion

The dignity of terminally ill children in pediatric palliative care is not the sole responsibility of any single entity. Rather, it is a collective endeavor that involves the active participation and cooperation of parents, healthcare providers, and the broader community. By embracing a holistic and person-centered approach, respecting the child's choices, and providing unwavering support, we can ensure that every child's dignity is preserved throughout their palliative care journey. Holistic pediatric palliative care recognizes that a child with a life-limiting illness is not merely a patient but a whole person with physical, emotional, social, and spiritual dimensions. Healthcare providers adopt a holistic approach that considers all aspects of the child's well-being, tailoring care plans to meet their unique needs and preferences. This approach means focusing not only on medical

interventions but also on the child's emotional and psychological needs, ensuring they receive comprehensive support during their illness. A person-centered approach revolves around the child as an active participant in their care. It involves taking the time to understand their wishes, dreams, and fears, and engaging them in discussions about their care to the extent they are able. Healthcare providers strive to create an environment where the child feels heard, respected, and empowered to make decisions about their treatment and end-of-life preferences. This approach reaffirms the child's sense of identity and agency, thus enhancing their dignity throughout the palliative care process. Respecting the choices of terminally ill children is a fundamental aspect of preserving their dignity. Each child's personality and values are unique, and it is essential to honor their autonomy, even in the face of challenging medical circumstances. This may involve allowing the child to make decisions about their treatment to the extent possible or ensuring that their preferences for pain management, comfort measures, and end-of-life care are respected [14]. Additionally, parents and healthcare providers must work collaboratively to strike a balance between the child's autonomy and their best interests. By engaging in open and honest conversations with the child and their family, healthcare providers can help navigate difficult decisions while upholding the child's dignity. Terminally ill children and their families require extensive emotional, psychological, and practical support throughout their palliative care journey. Parents play a crucial role in providing day-to-day care and emotional stability for the child, and they also need support from healthcare providers and the broader community. Social workers, counselors, and support groups can be instrumental in offering guidance and providing emotional support to both the child and their family. Beyond the immediate family, the broader community can contribute significantly to preserving the dignity of terminally ill children. Educating the community about pediatric palliative care can help dispel misconceptions and reduce stigma. Community members can offer support in various ways, such as providing respite care for parents, organizing fundraisers for medical expenses, or simply showing empathy and understanding. Preserving the dignity of terminally ill children is not just about addressing their medical needs but also about facilitating moments of comfort, love, and fulfillment during their remaining time. Healthcare providers focus on pain and symptom management to ensure that the child's physical suffering is minimized, allowing them to experience moments of peace and tranquility. Creating opportunities for the child to engage in activities they enjoy and spending quality time with loved ones can bring immense joy and fulfillment to their lives. The emphasis on creating a sense of normalcy helps the child feel cherished and valued, and it fosters an environment where their inherent worth as individuals is celebrated [15]. The journey of caring for a terminally ill child can be emotionally taxing for both families and caregivers. Preserving the child's dignity not only benefits the child but also leaves a lasting impact on those providing care. Knowing that their child's dignity was upheld, and their unique identity was respected, can provide comfort and solace to parents and caregivers during the grieving process. Compassion and empathy lie at the heart of pediatric palliative care. Through genuine care and understanding, healthcare providers and the broader community can make a profound difference in the lives of terminally ill children. Compassionate care acknowledges the child's suffering and validates their emotions, while empathy fosters a deep connection between the child, their family, and their caregivers.

## Conclusion

In conclusion, the dignity of terminally ill children in pediatric palliative care is a shared responsibility. Embracing a holistic and

person-centered approach, respecting the child's choices, and providing unwavering support are essential components of preserving their dignity. This approach enables terminally ill children to experience comfort, love, and fulfillment during their remaining time, leaving a lasting impact on their families and caregivers. Through compassion and empathy, we can celebrate the unique identities of these children and acknowledge their inherent worth until the end of their journey. By working together, we can create an environment of dignity, respect, and love, making the palliative care journey as meaningful and fulfilling as possible for these young patients and their loved ones.

### Acknowledgement

Not applicable.

### Conflict of Interest

Author declares no conflict of interest.

### References

1. Oluyase AO, Hocaoglu M, Cripps RL, Maddocks M, Walshe C, et al. (2021) The challenges of caring for people dying from COVID-19: a multinational, observational study (CovPall). *J Pain Symptom Manage* 62:460-470.
2. Mathew-Geevarughese SE, Corzo O, Figuracion E (2019) Cultural, Religious, and Spiritual Issues in Palliative Care. *Primary care* 46:399-413.
3. Radbruch L, De Lima L, Knaul F, Wenk R, Ali Z, et al. (2020) Redefining Palliative Care-A New Consensus-Based Definition. *J Pain Symptom Manag* 60:754-764.
4. Senderovich H, McFadyen K (2020) Palliative Care: Too Good to Be True?. *Rambam Maimonides Med J* 11:34.
5. D'Antonio J (2017) End-of-life nursing care and education: end of-life nursing education: past and present. *J Christ Nurs* 34:34-38.
6. Köktürk Dalcalı B, Taş AS (2021) What Intern Nursing Students in Turkey Think About Death and End-of-Life Care? A Qualitative Exploration. *J Relig Health* 60:4417-4434.
7. Lopes IM, Guarda T, Oliveira P (2020) General Data Protection Regulation in Health Clinics. *J Med Syst* 44:1-9.
8. Hui D, Bruera E (2016) Integrating palliative care into the trajectory of cancer care. *Nat Rev Clin Oncol* 13:159-171.
9. Schenker Y, Arnold R (2015) The Next Era of Palliative Care. *JAMA* 314:1565.
10. Schenker Y, Crowley-Matoka M, Dohan D, Rabow MW, Smith CB, et al. (2014) Oncologist Factors That Influence Referrals to Subspecialty Palliative Care Clinics. *J Oncol Pract* 10:37.
11. Muroya Y, He X, Fan L, Wang S, Xu R, et al. (2018) Enhanced renal ischemia reperfusion injury in aging and diabetes. *Am J Physiol Renal Physiol* 315:1843-1854.
12. Moresco RN, Bochi GV, Stein CS, De Carvalho JAM, Cembranel BM, et al. (2018) Urinary kidney injury molecule-1 in renal disease. *Clin Chim Acta* 487:15-21.
13. Crabbs TA (2018) Acute Kidney Injury (AKI)-The Toxicologic Pathologist's Constant Companion. *Toxicol Pathol* 46:918-919.
14. Lippe M, Johnson B, Mohr SB, Kraemer KR (2018) Palliative care educational interventions for prelicensure health-care students: an integrative review. *Am J Hosp Palliat Care* 35:1235-1244.
15. Martins Pereira S, Hernández-Marrero P, Pasman HR, Capelas ML, Larkin P, et al. (2021) Nursing education on palliative care across Europe: Results and recommendations from the EAPC Taskforce on preparation for practice in palliative care nursing across the EU based on an online-survey and country reports. *Palliat Med* 35:130-141.