

Challenges to Palliative Care in Pediatric Patients

Neha C¹ and Vivek K^{2*}

¹Department of Pediatrics, Maimonides Infants and Children's Hospital, Brooklyn, New York, USA

²Department of Internal Medicine, Maimonides Medical Center, Brooklyn, New York, USA

*Corresponding author: Vivek K, Department of Internal Medicine, Brooklyn, New York, USA; Tel: 718-765-2630; E-mail: vivkumar@maimonidesmed.org

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Introduction

The incidence of cancer is rising in pediatric population since last decade. In 2016, about 10,000 children are projected to be diagnosed of cancer in United States [1]. Though five-year survival rate in most of the pediatric cancer patients is more than 80% now [2], cancer remains the most common cause of mortality after trauma in age group 5-14 years [3]. The growing population of pediatric cancer survivors warrants parallel rise in the palliative care. As per the World Health Organization (WHO) palliative care is, 'An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' [4]. Notably contemporary thoughts advocate the integration of curative and palliative approaches in pediatric patients. Such comprehensive care mandates involvement of multidisciplinary team including physicians, nurses, child life specialists, social workers, chaplains and researchers.

The palliative care in pediatrics is evolving continuously, meeting new challenges and expanding beyond the care of terminally ill patients. The guidelines published by American Academy of pediatrics in 2004 was a major advancement in the field of palliative care [5]. Formation of Children's Oncology Group by merging various cooperative clinical trial groups in 2000 assisted in establishing recommendations for pain management and sedation for comprehensive pediatric oncology units [6]. Despite increased awareness and active efforts, this essential discipline of holistic care in pediatric patients is far from perfect. This paper aims to highlight the barriers in the delivery of palliative care to incurable pediatric cancer patients.

Discussion

Pediatric oncology units with multidisciplinary teams are growing in number in developed nations but are still very limited in underdeveloped countries with limited resources. Unfortunately, multidisciplinary teams are not always successful in overcoming social, biological and racial factors contributing to differential survival rates [7]. Approximately three-fourth of children suffering from cancer die in low- to middle-income nations [8]. Cost of financial burden of a multidisciplinary team is a major concern. In 2009 the estimated cost of hospital stay attributable to pediatric cancers was US \$859.8 million [9].

A major challenge is communicating with the patients and their families. Effective communication is the key to comprehensive palliative care but only few formal training courses exist for medical personnel [10]. The poor communication leads to inadequate symptoms management, impaired quality of life of the patients, false

expectations of care leading to either unwanted and aggressive therapies or non- implementation of simple interventions leading to worse outcome. The clinicians and family may find it overwhelming to discuss death with a potentially dying child. Concurrent use of interpreters, psychologist and child life therapists for explanation of death as part of imaginative play or using art/ music may lead to better acceptance and prevent depression or suicidal ideation in a very young child [11].

Emergency room is usually the first encounter of a patient and family in the series of encounters to a life changing event. Most of the times only urgent care is sought here due to the sudden progression of symptoms leading to acute crisis. The patient centered care in a busy emergency department for a terminally ill child is difficult and focus is mainly on the initial diagnoses with appropriate disposition. However open ended discussions with families about diagnosis, possible interventions, treatment and prognostication at the point of first contact may help guide their future choices and leave a great impact [12].

Although American Academy of pediatrics (AAP) recommends involvement of children in decision making [13], it may be difficult owing to their young age and less understanding. Participation of teenagers in medical decisions is encouraged [14]. The site of care whether home or hospital should be discussed with the patients in conjunction with their families and should be respected. Effective management entails maximum possible quality of care even in the terminal stages. But currently there is lack of information, training of health care professionals, investments and research to assess these factors in quality of care. Palliative care teams need to be involved early to discuss all the possibilities helping families in making informed decisions.

There is underutilization of opioids for symptoms control in pediatric patients. In 1990s WHO consensus guidelines recommended a ladder approach for prescribing analgesics based on pain severity [15] but common concerns include potentially hastening death or causing addiction [3]. Multiple studies have demonstrated no change in the survival of patients receiving high dose opioids for pain control, sedation or dyspnoea [16]. Though addiction is not a serious problem in children, physical dependence and tolerance occurs commonly. For prevention of withdrawal symptoms opioids should be carefully and slowly tapered while opioid rotation may prevent the development of tolerance [3].

Controversies over the role of palliative sedation in end of life care have given birth to the doctrine of double effect which implies extreme interventions with clear intentions of relieving the intractable symptoms even when death is foreseen due to the side effects of medicines [17]. However the families are unfortunately stuck in the dilemma of seeing their loved ones in immense pain and discomfort

versus consenting for intervention that makes them feel guilty of losing the loved ones forever.

There is increasing use of complementary and alternative medicine (CAM) integrated with standard medical treatment [18]. Prevalence of use of CAM therapies ranges from 31-91% in pediatric cancer patients [19]. CAM therapies are emerging as safe and compatible mind-body interventions (include herbal agents, music therapy and massages) to cope with overwhelming and life threatening diseases. Nonetheless only small trials have been performed to validate their effectiveness so far. Child Oncology Group (COG) conducted the first double-blinded, randomized, placebo controlled multicenter trial in 2004 to evaluate the effectiveness of a homeopathic remedy vs. placebo in the treatment of mucositis and demonstrated no statistical difference between the two [20]. Psychosocial support for patient and family is challenging especially in adolescent population in optimization of care and to reduce anxiety and depression. Hospice services entail emotional and spiritual support to the patient and family. Most agencies offer bereavement services to the community. An average of two family members received bereavement support from their hospice for each patient's death in 2014 [21]. Complicated or prolonged grief, behavioural and readjustment issues in daily routine can be handled with bereavement support to the family [3].

Pediatric Palliative / Hospice care (PP/HC) is a philosophy to integrate patient and family centered care to optimize the quality of life with expert services that may be delivered at home, freestanding hospice centers, hospitals and other long-term facilities [22]. The American Academy of Paediatrics had printed policy statement on PP/HC in 2013 [23]. Despite majority of deaths as inpatients, hospitals are not necessarily the preferred location for the families or patients. Advances in technology and insurance payment structures have facilitated delivery of complex medical care at home although numerous barriers still exist. Patient Protection and Affordable Care Act in 2010 was a major step towards integrating hospice care with curative disease directed therapies [24]. Children dying at home almost doubled from 10.1% to 18.2% over 15 years in a study conducted by Feudtner [25]. A study conducted in 2012 demonstrated significant reduction in monthly costs per patient, average number of days spent at hospital, stress and sleep disturbances with increased confidence among care givers of patients that received in-home services [25]. When patients and families are able to choose the preferred location of death as home, hospital or other medical facility in advance with the help of PP/HC services, they are more likely to be comfortable and prepared emotionally for the terminal event.

Conclusion

Palliative care is a comprehensive approach and its delivery to pediatric cancer patients is challenging. Through partnership with palliative care teams, appropriate information can be provided to the families about options for care to create a plan that addresses each patient's and family's goals. The palliative and curative approaches are not mutually exclusive in pediatrics. Studies are required to find innovative ways to increase the cost effectiveness of palliative care and maximize the satisfaction of patients and families while minimizing the burn out of medical personals involved in the care of dying children.

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