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The early integration of palliative care in pediatriconcology: a necessary challenge

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Abstract

Cancer in childhood and adolescence is an important source of physical, emotional, social and spiritual suffering, even with survivors rates showing considerable growth over the years. Palliative care in pediatric oncology aims to prevent and relieve this suffering, improving the quality of life of patients and their families. The earlier the introduction of these care during cancer treatment, the greater the benefit.

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Overall survival rates have increased along the years. However, cancer still ranks among the top causes of death for individuals in this age range.[1,2] An estimated 12,000 children aged 19 years or under have been diagnosed with cancer, with death rates ranging between 10-20%.[1] Ongoing advances in pediatric oncology have changed treatment paradigms and increased cure rates through the adoption of novel therapeutic approaches in which the disease is seen as a chronic instead of an acute condition.[3] This change in perspective has increasingly required the introduction of early palliative care alongside regular therapy to ensure improved quality of life and comprehensive support to patients and their families.

In 1998, the World Health Organization (WHO) issued one of the first publications to discuss palliative care for the pediatric population - "Cancer Pain Relief and Palliative Care In Children" - with recommendations dictating that palliative care be offered to children with cancer as soon as they are diagnosed with the condition, regardless of prognosis.[4] Other international organizations have also published relevant recommendations, which combined make up the landmarks for the introduction and implementation of palliative care in pediatric oncology. The integration of palliative care in pediatric oncology was declared a priority by the International Society of Paediatric Oncology (SIOP) in 1999 and by the American Academy of Pediatrics (AAP) in 2000. In a seminal paper published in the New England Journal of Medicine in 2000, Wolfe et al. showed that children with cancer die in significant pain and distress.[5] Several institutions have argued in favor of palliative care, since pediatric cancer is a severe, life-threatening condition permeated by a number of painful interventions and treatments, which culminates with decreased quality of life and significant distress.

The mission of palliative care in pediatric oncology is to provide high-quality communication, child and family-centered care and wellbeing, improved quality of life, and assessment and treatment of physical, psychological, social, and spiritual symptoms through the hands of an interdisciplinary team. Palliative care also helps when difficult decisions have to be made and enables care teams to resolve conflicts thoughtfully.[2,3] Effective communication is one of the tenets of successful palliative care. It helps develop trust and enables the continuity of care from the perspective of patients, their families, and the members of the interdisciplinary care team. Transparent empathic communication also creates a framework to identify patient and family-centered care goals, strengthen the bonds with the care team, and enable the making of shared decisions within the limits and information preferences of patients and their families.[3]

Another key aspect of palliative care in pediatric oncology is the management of symptoms of all orders. Pediatric cancer is known to cause high degrees of physical, psychical, social, and spiritual distress.[3] Levine et al. looked into the perspectives patients and their parents had on the distress they experienced during the first month of cancer therapy. The majority of the patients complained of nausea (84.5%), loss of appetite (75.2%), pain (74.4%), and anxiety (59.7%).[2]

Wolfe et al. interviewed 104 children with cancer aged two years or older and their families to find out more about their experience with symptoms. Nearly nine in ten (89%) of the 103 parents who answered the questions reported their children were in intense distress during therapy; 51% of the children had three or more physical symptoms that caused distress, the more common of which were fatigue, pain, dyspnea, and loss of appetite. Although the children were treated for symptoms, fewer than 30% of the parents thought there was any improvement from pain and only 10% indicated that nausea, vomiting, and constipation were properly managed. Although this study focused on end-of-life symptoms and distress, the authors indicated that managing both properly to improve quality of life - a task pertaining to palliative care - was a necessity. A study enrolling children and adolescents with advanced cancer based on a specific questionnaire (PediQuest) found that 38% of the respondents had fair or poor health-related quality of life. Scores in the physical and school subscales were the lowest. Thirteen symptoms were associated with decreased quality of life, including difficulty concentrating; preoccupation; dry mouth; pain; sadness; irritability; insomnia; fatigue; vomiting; and anorexia. Teams trained on palliative care in pediatric oncology are able to properly manage many of these symptoms.[2]

We believe that early palliative care is the best path to improving quality of life during cancer treatment and providing attention and care to the physical and psychosocial needs of patients and their families. Integral patient care clearly involves the search for a cure for cancer and the management of the symptoms tied to the disease.[6] When palliative care is provided merely as an end-of-life procedure reserved for individuals with advanced-stage disease, the opportunity to offer integral care to pediatric patients with cancer is missed. Families lose hope and sight of the need to provide child-centered care.[7] Snaman et al. discussed the role of oncology teams as the starters of child and family-centered care - a mission undertaken not only by providers of palliative care in pediatric oncology - as long as they have been adequately trained.[8] In such a setting, patients and families feel more supported by their oncologists, while palliative care experts may be called in when more specific or complex needs arise.[9]

Palliative care in pediatric oncology gains more significance as the disease progresses and chances of cure become slimmer. End of life is a period known for higher levels of physical, psychical, and spiritual distress. Interventions such as mechanical ventilation and painful invasive procedures, along with the environment in intensive care units, may result in a distressful physical and psychosocial experience. Evidence indicates that interventions of this kind are performed on a significant proportion of patients in the last month of life. A retrospective study on end-of-life care published by Kassam et al. found that 40.6% of the 815 patients enrolled in the study

were given high complexity procedures - including chemotherapy - within their last 14 days of life or were referred to intensive care units 30 days prior to their deaths. More than three quarters of the patients had pain, fatigue, and edema as the end of their lives approached. Fewer children and adolescents with cancer given palliative care were hospitalized in intensive care units. They also underwent fewer medical procedures and were more prone to discussing their prognoses and end-of-life goals with their families and caregivers. The involvement of palliative care teams has been associated with lower chances of intubation in the last 24 hours of life. Only 3% of the patients offered palliative care were provided cardiopulmonary resuscitation, versus 20% of the individuals not offered end-of-life care.[2]

The individualized support offered by pediatric palliative care teams helps patients and their families deal with the discomfort and distress inherent to the disease and families cope with the loss of their children to cancer.

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