
Palliative Care in Child Neurology: *The more you look, the less you see*

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Letter to the Editor

Abstract

Palliative care (PC) is holistic care of a child with a severe illness and his/her family which should begin soon after the diagnosis of a life-limiting illness is made. Communication forms the cornerstone of PC which begins with breaking the bad news in the right manner, continues in discussion with the family about their choices and expectations through life, and culminating in end-of-life and bereavement care. Raising awareness and developing PC services will eventually lead to a reduced burden on health-care systems, higher satisfaction rates and better quality of life for the children and their families.

Key words: palliative care, child neurology, communication

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Dear Editor,

In the rapidly evolving arena of "curative science", the past two decades have witnessed potential therapeutic advances for multiple neurological disorders that were earlier considered untreatable. Parallel to these therapeutic advances has been an evolution of the philosophy comprehending the sufferings associated with these diseases, the "palliative science." Palliative care (PC) started as a hospice centre for children in 1982 in Oxford (Worsewick J, 2000), and over the past four decades has developed into a more comprehensive care model that encompasses more than just the end-of-life care. The recently published consensus-based definition by the International Association for Hospice and Palliative Care defined PC as "the active holistic care of individuals across all ages" with serious health-related suffering (Radbruch et al., 2020). Their definition of holistic care includes early identification and management of suffering related to physical symptoms, emotional trauma, spiritual distress, and social needs, and prevention of disease/ distressing symptoms wherever feasible. This definition noticeably differentiates PC from hospice care. Hospice care implies care treating distressing symptoms towards the end of life. PC, as defined above, includes end-of-life care as a small subset. PC should begin as soon as a progressive neurological disorder is diagnosed alongside disease-specific management (Buhrfiend & Heydemann, 2018). PC in child neurology embodies palliative services not only for children with life-limiting primary neurological disorders but also for those with neurological involvement as a part of several other childhood-onset disorders.

Paediatric neurological disorders requiring PC include non-progressive (example cerebral palsy) and progressive (example leukodystrophies) neurological disorders that do not have a definite cure, and neurological disorders for which the possibility of cure is small (example (drug-resistant epilepsy). The leading neurological disorders requiring PC include Duchenne's muscular dystrophy, spinal muscular atrophy, brain tumors, neurodegenerative disorders, and sequelae of hypoxic-ischemic encephalopathy. The PC for these children involves active assessment and amelioration of their disease-related features and other associated co-morbidities. These include, but are not restricted to following disorders: gastrointestinal (feeding difficulties, gastroesophageal reflux, constipation), respiratory (hypoventilation, dyspnea,

recurrent respiratory tract infections), pain (secondary to spasticity, hip subluxation, urinary tract infection, constipation), sleep disturbance, seizures and other tonal/ movement disorders (spasticity, dystonia). Certain bedside examination clues and focused interventions like identification of weak cough (pointing towards respiratory weakness), use of cough assist device/thairvest, gastrostomy tube placement for maintaining nutrition, use of anticholinergic for drooling, screening for cardiac complications (especially in neuro-muscular disorders), bracing/casting for scoliosis, screening for hip dislocation (crucial for children with cerebral palsy) can lead to substantial changes in quality of life (Swaiman KF et al, 2018). Also, frequently these children have associated intellectual disability, which makes recognition of many symptoms like pain difficult. PC involves taking care of the family as a unit and not just of the child. This involves developing a support system for the families (parents and siblings) throughout the crisis. A questionnaire-based survey revealed that families require maximum support in the initial few months after diagnosis until they learn to cope - using various strategies that evolve as the disease takes its course (Davies, 1996).

The entire philosophy of PC is based on the fundamental premise of communication. Ongoing communication with the patient and family helps them understand the course of the disease and also aids the physician to discern their preferences and goals. Although it is challenging to initiate advanced care planning, especially in a resource-limited set-up, it leads to higher compliance and satisfaction with PC and reduction in unnecessary interventions in end-of-life care (Voss et al., 2017). SPIKES (setting, perception, invitation, knowledge, emotion, and summarize) and NURSES (Name, understand, respect, support, and explore) are commonly used protocols for communication with parents ("Communication," 2008). In addition to communicating about the pharmacotherapy, PC also involves providing the spiritual, psychological, and emotional support to the family and patient. Also, the family support may include discussion about the comfortable environment for dying that should balance out between the necessary medical/ nursing care and also simultaneously provide privacy to child and family members. Besides communication with the family, the significance of age-appropriate conversation with children about their illness is being

increasingly recognised. A well-timed discussion which is appropriate for the developmental and chronological age of the child can alleviate the high anxiety levels in children with life-limiting illnesses (Muckaden et al., 2011).

With increasing survival rates of children with life-limiting diseases due to advancing medical care, parallel strengthening of PC services are of utmost importance (Lyons-Warren, 2019). Boosting the PC services will also reduce the workload in a busy neurology set-up by channeling eligible children and families to PC clinics wherein their concerns can be addressed by a multi-disciplinary team. The development of PC services may seem to be a luxurious undertaking in low-to-middle income countries. Still, it may, in turn, be cost-effective by reducing the number of unnecessary interventions and inpatient admission during in end of life care, which can be discussed with the family beforehand in PC clinics. Lastly, the awareness about the scope and principles of PC should be increased not only amongst health-care professionals but for caregivers as well, because their participation forms the foundation stone for wholesome palliative care.

Conclusions

Palliative care is an evolving paradigm which incorporates disease-specific treatment, symptomatic management of co-morbidities, supporting the children and their families, hospice care and bereavement support. Uplifting the palliative care services is the need of the hour as medical science continues to advance.

Conflicts of Interest

Authors declare no conflict of interests.

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