Pediatric Palliative Care Medicine?

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Pediatric palliative care is often misunderstood and often enters in to a child and families lives too late. The overall goal of pediatric palliative care is to improve the quality of life for a child with an underlying life-threatening illness or problem. It focuses on prevention and relief of suffering, regardless of the stage of disease, and comprehensively addresses the physical, psychosocial, or spiritual needs of the child and family. The World Health Organization (WHO) describes pediatric palliative care as "the active overall care of the child's body, mind, and spirit, and involves providing support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease". It is hoped that families of infants and children with a diagnosis where cure may not be possible are introduced to the palliative care team at the time of diagnosis, yet often is this the case. Palliative care for children ideally should be introduced from the beginning of diagnosis or treatment as it helps to ensure an ongoing focus on quality of life and relief of symptoms, so the child may continue to enjoy life.

A child's well-being should always be the primary guide to all for care for each individual child. The role of the parents and providers is to watch and listen intently, and then to reflect honestly on what is in the best interest of that particular child. This plan should include a reflection on the benefits and possible adverse effects of past intervention as well as the expected outcomes of current and future treatments. In order to avoid any misunderstandings, it should always be made clear to the families that the entire care team (treating physicians, palliative care, etc) is not trying to limit treatments that may have a reasonable benefit. The overriding goal is always to protect the child from interventions with little or no benefit or that may harm or prolong suffering, and to provide care that enhances the child's comfort.

Perinatal palliative care is assisting mothers, fathers and families facing a life-threatening fetal diagnosis and involves its own set of unique challenges, however, still utilizing the same palliative care principles outlined above. Families can benefit from the opportunity to prepare and plan before delivery of their infant. The palliative care team offer supportive care for the mother prior to and during labor and delivery and helps to plan the care for the baby. Communication is a vital part of planning and preparation so to ensure that interventions are consistent with the parents' goals for their baby. This may involve a decision to not resuscitate the infant, rather focus on the baby's comfort. When the infant survives, and if appropriate, parents may choose home-based palliative or hospice care.

Although the principles of pediatric palliative care are similar to that of adults, implementation of their care is considerably different due to the following:

- *There is a wide range of growth, development and cognitive abilities as well as the emotional maturity of the infant, child or teen*
- *There are differences in the causes of illness or problems*
- *In dealing with a child it is imperative that the palliative care team work closely with the child, the parents, siblings, and the educational system*
- *Legal decision-making authority with regard to the child's care resides with the parents, not the child, although "assent" to treatment should always be offered to a child capable of understanding*

Palliative care for infants and children requires consideration as a distinct and unique specialty involving those experienced in pediatric care. Palliative care provided to children and their families must be child-centered, family-centered, holistic and multi-disciplinary. There must be flexible, comprehensive, and age appropriate care for these infants and children who require a variety of services and skills for the whole family, including siblings.

There are many childhood conditions which differ from that of adults, and thus pediatric palliative care may stretch over many years. Children continuously develop physically, cognitively and emotionally which influences both their medical and social needs and their on-going understanding of their disease or condition. Unfortunately, formal training in palliative care for children, although increasing, is not widely available, certainly not in Northern Nevada, which has a bearing on the setting of standards and protocols but also on much needed funding for these fragile children.

Children with chronic conditions, such as congenital anomalies, cystic fibrosis, severe neurological impairment, and many other conditions, may benefit from palliative care if symptoms are difficult to manage or if there is significant suffering physically, emotionally or spiritually. This often becomes evident at a time of decline in health status, which results in uncertainty regarding outcome, and impacts quality of life as reported by WHO.

Optimistic estimates of prognosis are often a barrier to initiating a pediatric palliative care consult. Nevertheless, the introduction of palliative care does NOT mean that curative treatments aimed at reversing the disease process when cure is unlikely or not possible need to be stopped. Research has supported that the integration of palliative care does not lessen a parent's hope, and prognostication that some clinicians consider disturbing and upsetting does NOT diminish a parent's desire for this information rather it is imperative to the informed decision-making process.

Pediatric palliative care understands there is always caring to provide: attention not only to the physical symptoms, but to the whole child and entire family emotionally, socially, spiritually, academically, and with regard to growth and development regardless of the clinical situation. When the prognosis is poor, palliative care has the positive benefit of being able to prepare the child and their families for bereavement. Parents and children who are not prepared for addressing quality at the end-of-life tend to choose more intensive and invasive interventions that often prolong suffering at the end-of-life.

Successful pediatric and perinatal palliative care should include the following:

- *An interdisciplinary team: one person does not have the time or capability to address the multiple care needs of the child and family*
- *Developing a committed relationship between the healthcare team, the child and family*
- *Effective communication and accessibility are crucial to successful palliative care*
- *Decision-making for on-going treatment based on the goals of care for the child and family rather than treating a clinical problem in isolation helps to avoid the consequences of providing interventions out of a sense of needing to 'do something' when parents and clinicians become distressed over the limits of medicine. The plan of care needs to adapt to the change in the needs of the child and family as the disease progresses*
- *Managing symptoms (pain, nausea, vomiting, anorexia, respiratory distress, depression, anxiety, sleep disturbances, seizures, etc) due to the underlying disease process; this management must include anticipating and preventing symptoms as much as possible*
- *Preparing children and their families for end-of-life care, which includes bereavement support*

The interdisciplinary team (IDT) typically includes a physician, advanced nurse practitioner, pediatric registered nurse, chaplain, social worker, and child life specialist as well as administrative staff to assist with insurance, billing and equipment so necessary to the child's care. The IDT helps to ensure that the emotional, spiritual, physical and practical needs of the children and their families are identified and met. Additionally, the palliative care team is also able to provide a supportive environment and assist other healthcare team members in managing their own distress and grief in dealing with a seriously ill child.

"Pediatric Palliative Care": Being the quarterback for infants, children and their families"

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