

Pediatric Palliative Care

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Children die every day. To many people, this seems unbelievable, and yet, to the families and friends of the more than 50,000 children who die each year in the United States, it is a grim reality. Just over half of these deaths occur in the first year of life, mostly from congenital anomalies and issues related to prematurity. The most common causes of death after the first year of life include unintentional injuries, congenital anomalies, cancer and intentional injuries.¹ Nearly 200 of these deaths occur in children from South Dakota each year.² While many of these deaths are unexpected as the result of injuries, the majority do not happen acutely. In fact, each year 500,000 U.S. children and their families cope with life-threatening illnesses.³ Thus, there is a need and an opportunity to introduce palliative care to help children, along with their siblings and family members, better prepare for and cope with the possibility of death.

The terms palliative care and hospice are often used interchangeably and are unfortunately misconstrued by some to signify giving up hope. Palliative care is the treatment of any symptom – physical, mental or emotional. Hospice is a subset of palliative care provided to children or adults with a terminal illness. The main goal of hospice, and of palliative care, is to maximize quality of life.⁴

When we as health professionals talk about palliative care, it tends to be after all or most available medical therapies have been tried. Instead of practicing according to the traditional model, which treats people who cannot be cured only at the end of their illnesses, we should strive to practice according to the model laid out by the World Health Organization (WHO), which advocates for early involvement of palliative care services for those who are at risk of dying.⁵ If curative measures do not work, then the palliative care service can begin to take a more active role. In this model, a palliative care team has been involved for some time and has been able to establish a relationship with the patient and family. This allows for more seamless care than the model in which palliative care is introduced only at the end of the illness.

In palliative care, as in all aspects of medicine, children cannot be treated simply as small adults. Most palliative

care and hospice programs have been centered on adults, but children have unique needs. For example, children of all ages differ from adults and from each other in terms of their understanding of death. How children understand death depends on their developmental level as well as their families, cultures and personal experiences. A fully mature understanding of death requires integrating the principles of irreversibility (death is permanent), finality/non-functionality (all life-defining functions and emotions end at death), universality (all living things die), and causality (illnesses or events cause death). Children achieve these levels of understanding at different ages, but it is thought that children understand death as a changed state as early as 3 years of age, universality by about 6 years of age and personal mortality by about 9 years of age.³ Thus, it is important to recognize that dying children generally know that they are dying. Avoiding the topic does not protect them, but rather it denies them the ability to talk about their feelings and breeds fear and isolation.⁶ Children, like adults, have hopes and fears and dreams about the future and, ill or not, should be encouraged to share them.

Just as children are different from adults, palliative care programs for children must be different from those for adults. The WHO affirms that “palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.” It charges health providers to evaluate and alleviate a child’s physical, psychological and social distress.⁷ This vision of palliative care requires a multidisciplinary team (Table 1) that is best involved early in the disease process rather than when death is imminent.

Team members, while having discreet responsibilities, also share many overlapping skills and duties and need to be open to adapting to individual cases. Collectively, they can address the varied needs of children and families. Donnelly et al. suggested seven needs that are important to incorporate into a comprehensive model of pediatric end-of-life care.¹¹ (Table 2)

One of the primary goals of palliative care is the relief of physical suffering. Numerous symptoms may occur and can be as varied as the disease processes themselves. The ability

Table 1.
Team Members for Pediatric Hospice and Palliative Care Services^{8,9,10}

1. Physician director
2. Nurse coordinator/Case manager
3. Nursing
4. Social Worker
5. Child Life
6. Psychologist/Mental Health Worker
7. Respiratory Therapists
8. Pastoral care
9. Pharmacist
10. Bereavement counselor
11. Dietary
12. Physical, Occupational and Speech Therapists
13. Home care agencies
14. Family/Parental Support Volunteers

to assess for these symptoms in children of different ages is a necessary skill for the physicians and nurses. The treatment of these symptoms can be facilitated by a pharmacist with the ability to compound medicines for pediatric dosing and delivery. Common symptoms experienced by children at end of life and often requiring treatment are pain, nausea, vomiting, fatigue, anxiety, constipation, dyspnea and seizures.¹⁰ A supply of compounded medicines, individualized for each patient, can be made available to each family for these symptoms and any others that may arise as the child's condition dictates.

It is important to note that the relief of physical symptoms is but one goal of palliative care. Palliative care and hospice can provide anticipatory guidance and shared decision-making for parents and children, as well as family-centered care to include parents, siblings, grandparents, close friends, teachers, classmates and other important members of the child's social circle.¹² Child life members serve a particularly important role by providing age-appropriate information to children and siblings using varied strategies to promote communication, understanding and memory building.

Table 2.
Pediatric Needs to Be Addressed at the End of Life¹¹

1. Pain and symptom management
2. Decision-making
3. Access to the medical system
4. Dignity and respect
5. Family-oriented care
6. Spirituality
7. Psychosocial issues

Child life, along with mental health counselors and social workers, can provide psychosocial and emotional support while pastoral care can address spiritual issues. Davies et al. state that spirituality, which is not the same as religion, faith or psychosocial need, has often been neglected in medical care. Spiritual needs exist independent of religion.¹³ Spirituality should be addressed with the goal of "assisting individuals to find meaning and purpose in life, to continue relationships and to transcend the self."¹³ In their article, numerous guidelines are provided to aid team members in addressing these issues in children, parents, siblings and grandparents.

Ongoing interactions with the family to provide psychosocial, emotional and spiritual support can continue after the child's death. This critical component of hospice, namely bereavement services, is available to families for one year after the death of their child if they were enrolled in hospice.

Palliative care provides an absolute benefit to children and families. So why are so many children not receiving these services? Numerous barriers to pediatric palliative care have been identified. (Table 3)

Table 3.
Some Identified Barriers to Pediatric Palliative and Hospice Care^{9,12,15,16}

1. False hope of cure among caregivers or health professionals
2. Delayed identification of need
3. Lack of understanding of pediatric palliative care
4. Lack of providers trained in pediatric palliative care
5. Distance from services
6. Disallowing concomitant chemotherapy or other treatments
7. Inadequate or fragmented follow up care after discharge
8. Poor continuity of care across hospitalizations
9. Inattention to spiritual or psychosocial issues
10. Inadequate financial support

While adult hospice and palliative care programs are well established in this country, dedicated pediatric programs lag far behind. Two major factors accounting for this are epidemiology and finances. While 50,000 pediatric deaths nationwide is a staggering number, it pales in comparison to the number of adult deaths that occur nationally each year. This smaller number, along with the reality that these children are scattered throughout the country, makes it more challenging to develop programs and resources to serve all children. Financial support is also a critical issue for many programs as reimbursement for palliative care for children often falls short of that for adults. To date, a

national uniform payment scheme (i.e., the hospice benefit with Medicare) does not exist for children. Additionally, children with complex medical needs require many medications, nutritional supplements and durable medical goods that may not typically be covered by hospice benefits.¹⁴ Thus, programs specifically focused on children can be hard to establish and even more difficult to maintain.

One barrier to enrollment in hospice services, even where available, has been a desire to continue certain medical treatments that have traditionally been viewed as curative and, therefore, not allowed for patients who enter hospice. These treatments, which include chemotherapy, surgery, radiation or transfusions, often affect children with cancer. The desire to continue these treatments is reported to be the most common reason for not referring a child to hospice by pediatric oncologists,¹⁵ thus depriving them the benefit of hospice services. A hospice that allows such palliative treatments, and all the aforementioned treatments, may increase the number of children and families receiving comprehensive hospice care.

As previously stated, infants and children of different ages have different needs based upon their developmental stage. There is a growing awareness of another “pediatric” group that can benefit from the provision of hospice care. With technological improvements in prenatal diagnosis, more fetuses with life-limiting anomalies or genetic disorders are being identified. For women who choose to not have an abortion, expecting that the child will die shortly after birth, the availability of a perinatal hospice can provide tremendous support. This type of hospice provides psychosocial support, information and resources to families “as they plan for both the birth and often probable death of their child,”¹⁷ as well as opportunities for memory building. One such team in Minnesota is comprised of a nurse, a social worker, a chaplain and parent support volunteers who work with the obstetric team. Personal choice is a “central element” in the development of care plans that include the choice to terminate the pregnancy.¹⁷

In conclusion, as technology improves and more and more children are surviving prematurity, congenital defects and critical illnesses, it becomes easier to regard death as avoidable, yet the numbers prove otherwise. If we do not discuss the possibility of death either because we practice in this age of the technological imperative or because of our own personal discomfort, then we deny children and their families the time and support they need to prepare. Multidisciplinary palliative care teams can maximize the quality of life for ill and dying children and their families.

With a growing awareness of need, improved education and resources, and a collaborative approach between health care providers, families and the palliative care team, many of the barriers to palliative care can be overcome. The challenges in pediatric palliative care are great, but the needs are much greater. It is time for us to move forward and provide the children of South Dakota and their families with much-needed pediatric palliative care.

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