

Palliative Care and the Family

Pediatric palliative care is a philosophy of patient care that focuses on reducing suffering while helping children and adolescents with complex medical conditions to live full and meaningful lives. Family-centered care is particularly important when helping a child or adolescent and family adapt to a serious or life-threatening illness. Palliative care respects the individuality of each family's culture while supporting the physical, psychological, social, emotional, and spiritual needs of the seriously ill child or adolescent. This entry discusses the history of palliative care in Western medicine, ethical issues in pediatric life-threatening illness, the components of pediatric palliative care, the desired individual and family health outcomes, recommendations for interventions and programs to promote individual and family well-being, and relevance of palliative care to broader issues of family health.

The History of Pediatric Palliative Care in Western Medicine

Most developed countries have seen the eradication of childhood diseases that previously resulted in death. Vaccinations, antibiotics, advances in genetics and molecular biology, prophylactic treatments (treatments that prevent disease), and improved technology account for fewer deaths from disease in the pediatric population. Still, each year in the United States, approximately 50,000 children (birth to 19 years old) will die. Although approximately half of these deaths occur from accidents, experts believe that there are a significant number of individuals and their families who are facing a life-threatening illness, such as cancer, cystic fibrosis, complications related to premature birth, congenital malformations, or end-stage renal disease, who could benefit from pediatric palliative care services.

Pediatric palliative care evolved from the philosophy of hospice. The first hospice center originated in London, England, in 1967 under the guidance of a physician named Cicely Saunders. Saunders was first a nurse and a social worker, who believed in the importance of providing holistic care to the dying patient. As a physician, she contributed to our understanding of pain management by introducing the concept of total pain, which includes not only physical pain but also emotional, social, and spiritual pain as well. The hospice movement spread to the United States and other Western cultures in the 1970s and 1980s, with the development of pediatric hospice first occurring in 1978. Today, in the United States, Medicare, private insurance companies, and most state Medicaid programs include hospice coverage so that dying patients have the option to be treated by a licensed hospice provider either at home, in a health care facility setting, or in an independent hospice center. There are approximately 8,000 hospices in 100 countries around the world.

The hospice philosophy supports pain management and symptom control while addressing the painful emotions associated with grief and loss. Hospice focuses on living while dying and neither hastens death nor postpones death. Pediatric palliative care embraces the same principles but is extended across the treatment trajectory and can be implemented even when the treatment goal is curative. For example, when a child undergoes a stem cell transplant, very high doses of chemotherapy are given prior to the transplant to ensure all of the cancer cells are gone before the new "cancer-free" cells are given. The chemotherapy that was given to cure the disease causes some of the good cells to be destroyed as well. When cells that line the mouth and throat are damaged, painful sores can develop. This makes it very difficult to swallow or eat. Palliative care treatments would address the issues that are affecting quality of life. In this case, it is pain, which in turn affects a child's

ability to eat. In this situation, a child is given a continuous intravenous infusion of pain medication at whatever dose is needed to relieve pain. The need for pediatric palliative care became evident as children and adolescents began to live longer with life-threatening diseases. Although certain diseases remain incurable, modern medicine has allowed individuals to live many months and sometimes years with an advanced or incurable disease. Some argue the length of a person's life is not nearly as important as the quality of how life is lived. Therefore, palliative care programs were initiated in hospitals and health care facilities to address this important quality-of-life need.

The philosophies of hospice care and palliative care are similar in their holistic approach to address the physical, psychological, emotional, social, and spiritual needs of the individual facing a life-threatening illness. However, there are a few differences worth noting that are described in Table 1. A limitation to the provision of hospice services to adults or children is the stipulation that a physician must determine an individual has 6 months or less to live. This is mandated by the U.S. federal government. Federal laws on hospice care are meant to provide a uniform standard of care. Additionally, hospice reimbursement restricts curative treatments when an individual is receiving hospice services.

Insufficient access to pediatric hospice services in rural areas makes it difficult for some children to receive hospice services in their home communities. As a result, many individuals are not adequately covered by a hospice provider or are referred to hospice late in the disease process. This in turn results in more children dying in an acute care setting, such as a hospital. Studies have shown that individuals with terminal diseases prefer to die at home; however, more than half of the children and adolescents with complex chronic conditions, such as incurable cancer, die in a hospital setting with measures directed at sustaining life. In 1983, Children's Hospice International (CHI), a nonprofit organization, was founded with the purpose of addressing hospice and palliative care needs in children and adolescents. Today, organizations such as CHI are working with existing health care facilities, community agencies, and lawmakers in the United States to coordinate interdisciplinary, collaborative, palliative, and end-of-life hospice care so that parents do not have to choose between curative versus hospice treatments for their child with a life-threatening disease. The historical development of pediatric palliative care is summarized in the time line in Figure 1.

Table 1 Differences Between Hospice and Palliative Care

<i>Hospice Care</i>	<i>Palliative Care</i>
Initiated for incurable or terminal illness	Initiated any time during a serious or life-threatening illness
Curative treatments generally cannot be administered at the same time as hospice services	Curative treatments can be administered at the same time as palliative care services
Physician determines an individual has 6 months or less to live prior to initiation of hospice services	Palliative care can be initiated any time from point of diagnosis and throughout illness to cure or end of life
Reimbursement is limited to the last 6 months of life	Palliative care services are reimbursed at any point in the disease process
Primary focus is to relieve suffering during end-of-life care	Primary focus is to relieve suffering at any time in the disease process

Provides bereavement support to the family immediately following death

Bereavement support after death varies according to each institution but is often neglected in pediatric acute care settings, such as hospitals

Ethical Issues in Pediatric Life-Threatening Illness

Modern medicine has allowed many children with chronic, life-limiting childhood diseases, such as cystic fibrosis, to live long enough to go to college, have a career, and start a family of their own. Improvements in pediatric oncology treatments have increased the cure rate to 80% for some childhood cancers. Health care professionals have become more comfortable treating childhood diseases aggressively and less comfortable facing the possibility of death from disease. Studies have shown that health care professionals struggle determining when curative efforts have been exhausted. The uncertainty of not knowing if or when a child is truly dying creates ethical challenges for delivering pediatric palliative end-of-life care. Consequently, discussions about end of life and the inability to cure disease occur very close to death in the pediatric population, leaving insufficient time to adequately prepare for death. Most of the ethical issues in pediatric palliative care revolve around communication and the child's or adolescent's involvement in decisions. In pediatrics, the standard of care is shared decision making between the family unit (which consists of the parent[s] and child or adolescent) and the medical team. Ideally, information about diagnosis, treatment options, and prognosis is openly discussed with the child and adolescent in an understandable language. This type of communication is based on openness and honesty within a supportive environment. Open communication builds trust and facilitates respect. Open communication allows the child or adolescent to have an active part in decisions about care while encouraging the discussion of fears and concerns throughout the disease process. However, as disease progresses, decisions become more difficult. Some decisions involve informed consent about experimental therapies. Other decisions involve advance directives or do not resuscitate orders. If decisions about advance directives and end-of-life care are not addressed openly and honestly to establish the goals of care, then families and health care providers find themselves faced with even more difficult decisions at a time of crisis. These decisions may involve withholding or withdrawing life support. An essential component of end-of-life palliative care is open communication about the goals of treatment so that the focus at end of life can be living a quality life that is congruent with the young child or adolescent and family wishes.

The child's or adolescent's cognitive and emotional development influences involvement in decisions. Moreover, children and adolescents under the age of 18 are not legally able to consent for treatment in the United States. However, studies have shown most adolescents want to be involved in decisions about their care even when the prognosis is life threatening. Experts in ethics agree that children as young as 7 years old should receive information in an understandable language so that they can give written and verbal assent for treatment and be involved in their plan of care.

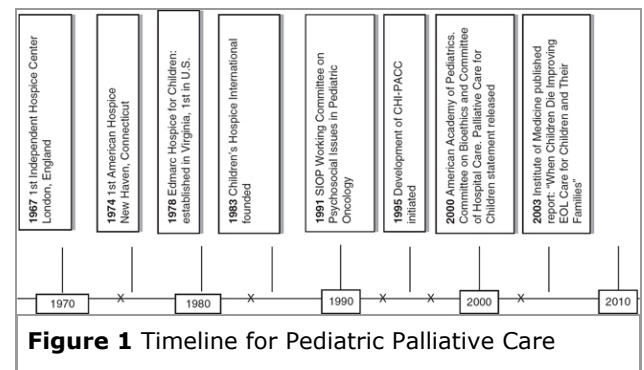


Figure 1 Timeline for Pediatric Palliative Care

Studies have shown that children or adolescents with a life-threatening disease have an understanding of death that far surpasses the developmental level of their healthy peers. However, the seriousness of the decision also impacts how comfortable adults feel in discussing the situation with the child or adolescent. It is believed that protection plays an important role in these intimate conversations.

The philosophy of pediatric palliative and hospice care embraces open and honest communication about diagnosis and prognosis with the child, adolescent, family, and health care provider. This is a value that is consistent with Western cultures (North America, Europe, and Australia). Other cultures, particularly Asian and

Hispanic cultures, do not necessarily believe that open communication about serious or life-threatening illness is beneficial to the individual. There are unique palliative care needs in these populations. It is important to consider each child's or adolescent's palliative care needs within the context of the family culture. Emerging research supports open communication to reduce distress for the dying individual. Yet more research is needed to understand the impact of open communication in families of diverse culture.

Components of Pediatric Palliative Care

There are several components in pediatric palliative care that are essential to deliver quality care. They are (a) creating a care context that is family centered and age appropriate, (b) providing individualized care to the child or adolescent, (c) attending to symptom management (addressing the physical, psychological, emotional, and spiritual needs of the child or adolescent), (d) facilitating communication within the family and between health care providers and the family, (e) coordinating an interdisciplinary approach across hospital and community settings, and (f) advocating for participation in decision making. Each of these components is addressed in the following sections.

Family-Centered and Age-Appropriate Care Context

Truly the family is the unit of care when a child or adolescent is sick or dying. However, it is equally important to consider the developmental level of the child or adolescent and to deliver care that is age appropriate. A child goes through many developmental changes from birth to adulthood. In addition to physical changes, there are social, cognitive, and psychological changes. Developmental theorists, such as Erik Erikson, Sigmund Freud, Jean Piaget, Albert Bandura, and Lev Semonovich Vygotsky, have their own influential theories that describe and explain development. When a child or adolescent has a serious or life-threatening disease, there is a natural tendency to treat the child or adolescent as developmentally younger than other peers their age. This may partially be due to the fact that a child or adolescent becomes more dependent on others during times of serious illness. Additionally, parents and health care providers naturally want to protect the child or adolescent from further emotional harm due to the multiple losses the child or adolescent and family are facing. Although the desire to protect is made out of love, the child or adolescent suffers socially and emotionally. If the child or adolescent is not included in developmentally appropriate discussions about the seriousness of disease and potential complications including the possibility of death, then he or she is left to imagine all of this when socially isolated from their main source of support, the family. Embracing the family unit at the point of diagnosis and including the child or adolescent in age-appropriate discussions creates an open and honest care context. The family-health care provider relationship becomes a safe and trusted relationship where the child or adolescent can find respite without the fear of abandonment if cure is not achieved.

Individualized Care

People want to feel as if their lives matter. Additionally, parents of children or adolescents who are seriously or terminally ill want their child to be known as an individual person. This is where the humanistic approach to medicine becomes very important. Taking the time to get to know each child and his or her unique interests is crucial to the provision of excellent palliative care. One of the concepts identified by families as an outstanding practice in palliative and end-of-life care is *nonabandonment*. The ability to be present, to sit and listen and to pay attention to what makes each person unique, is central to individualized care. Some children like dinosaurs, some like sports, others like music, and still others like none of the above. Within each of these categories is a lot of diversity. By taking the time to get to know seriously or terminally ill children as individuals, one can tailor interventions specifically to match their needs. Individualized care delivered at end of life has been shown to decrease distress in bereaved family members after the death of a child or adolescent. Individualized care also promotes dignity by affirming the unique characteristics of the individual who is seriously or terminally ill. Individualized care not only acknowledges the individual but also acknowledges the unique culture of the family unit. Family beliefs and cultural practices can be incorporated into the delivery of palliative care. Individualized

palliative care is built on respect for the diversity of each individual within his or her family unit.

Symptom Management

One of the most important aspects of palliative care is to reduce or alleviate suffering. Watching someone suffer needlessly is simply unacceptable. There are ways to provide comfort to individuals who have pain or are having trouble breathing or who are suffering with anxiety or severe nausea and vomiting. Sometimes, medications are used; other times, relief is provided through strategies such as the human touch or simply being present and listening. In each instance, palliative care takes into account all the symptoms that could possibly cause distress and affect quality of life and initiates ways to provide comfort and support.

Initially, quality-of-life research focused on relief of physical symptoms, such as pain. Eventually, it was determined that physical symptom distress was only one aspect of suffering related to a life-threatening disease. There is also emotional, psychological, social and spiritual or existential suffering that can occur with serious, life-threatening, or terminal diseases. Addressing symptoms holistically is an important component of pediatric palliative care.

Physical symptoms vary according to disease and side effects from treatment. For example, cardiac and respiratory diseases may have more symptoms related to fatigue or shortness of breath. Individuals with cancer may have pain, nausea, and vomiting in addition to fatigue and dyspnea as prevalent symptoms. As disease progresses to end of life, fatigue becomes one of the most frequent symptoms. It is particularly distressing in pediatrics because it is disproportionate to the amount of activity and is unresponsive to rest. Fatigue significantly impacts quality of life. Pain is also very prevalent and requires an aggressive and proactive stance to achieve comfort. When managing symptoms, it is important to identify the severity of the symptom as well as the degree of bother, or how much it interferes with everyday living. The most common physical symptoms reported in children with life-threatening or terminal diseases include pain, fatigue, weakness, dyspnea, weight loss, anorexia, vomiting, constipation, and diarrhea. Managing distressing physical symptoms that interfere with quality of life are necessary before psychological, emotional, and spiritual needs can be addressed.

The most prominent psychosocial symptoms reported in the pediatric palliative care literature include depression, sadness, anxiety, nervousness, worry, guilt, loneliness, and fear. There have been some studies done to describe a child's or adolescent's awareness of impending death when diagnosed with incurable cancer. There has been much distress reported when an adolescent or child is not given the opportunity to discuss his or her fears and uncertainty. Additionally, the developmental age of an individual greatly influences his or her psychological response to life-threatening and terminal disease. In a recent study conducted by J. M. Theunissen and colleagues, the physical, psychological, and social symptoms of children and adolescents at end of life were reported by their parents. There was a significant difference in psychological symptoms for adolescents over the age of 12 compared to children under the age of 7. The most frequently reported psychological symptoms at end of life in the adolescent age group were sadness, loss of perspective, loss of independence, fear of physical symptoms, and fear of death. More work needs to be done to address the psychological distress that children and adolescents experience while facing death. Providing the opportunity for children or adolescents and their families to acknowledge and express their grief is an important first step for providing the social support needed to face this painfully challenging time.

As disease progresses to end of life, symptoms may increase in intensity. Several pediatric end-of-life studies conducted in the past decade have described significant physical and psychological suffering in dying children and adolescents as reported by their families and health care professionals. Fear, along with pain and other physical symptoms, is prominent at end of life, yet many physicians and nurses report discomfort in managing end-of-life symptoms, particularly in children. As a result, children and adolescents are dying from incurable diseases without adequate support to face the physical, emotional, psychological, social, and spiritual issues that are a normal part of dying. This has resulted in global initiatives to incorporate pediatric palliative care from

the time of diagnosis to either cure or end of life. Hospitals and tertiary care centers are beginning to evaluate current pediatric palliative care services to determine where education and supportive services are needed to improve end-of-life care, not only in the United States but also in Canada, Sweden, Australia, and the United Kingdom as well.

Open Communication

Communication can be particularly challenging when a child has a life-threatening or terminal disease. Studies have repeatedly shown that improved communication is needed particularly as disease advances. An effective palliative care program facilitates communication both within the family unit and among the family members and health care providers. Communication is needed from the point of diagnosis onward to provide valuable information to parents and children or adolescents, so they can make informed decisions. Parents want open and honest information presented in clear, consistent, and understandable language. Increased knowledge that is gained through compassionate open communication also helps the family to have a sense of control over a situation that feels very unmanageable.

Open communication is a skill that can be learned and modeled for families facing a life-threatening disease. Open communication in pediatric palliative care is defined as ongoing honest discussions about illness experiences (e.g., diagnosis, prognosis, treatment, death, and dying) where both positive and negative thoughts and feelings are freely exchanged and accepted without bias. Ongoing communication is necessary to better prepare individuals and their families for advanced disease and the possibility of death. Studies have shown that children who are dying are aware that death is imminent and experience anxiety related to the dying process. Open communication allows the child or adolescent to talk about their grief and loss. When communication is constrained, the child or adolescent faces death in social isolation.

In Western cultures, open communication in pediatric palliative care is thought to have more benefits than risks. Benefits include being able to process distressful thoughts and feelings in an environment of support and trust, reducing anxiety related to fears, decreasing feelings of social isolation, promoting control through shared decisions, and providing the opportunity for closure by discussing opportunities to fulfill wishes, make memories, and say goodbyes. Some risks to open communication as perceived by health care providers include fear of taking away hope, worry that talking about death will increase parent or child distress, and worry that skill and training are inadequate to navigate discussions about death.

Studies have consistently identified the need for better communication in pediatric palliative and end-of-life care. Health care providers identify the need for more training in discussions about death, particularly with children and adolescents. Research on end-of-life communication in the adult literature is focusing on identifying emotionally charged conversations and the physician's personal reaction during conversations. Training is then tailored to each physician to facilitate conversations about poor prognosis or impending death in a compassionate and understandable way with an emphasis on conveying nonabandonment. Additionally, there are some studies that are tackling the issue of hope. Hope is an important attribute that propels the human spirit. Facilitating conversations that include both hope and at least one pessimistic comment help dying patients to be more aware and accepting of the dying process. As disease progresses, health care providers and families can change the focus of their hope, from hope for a cure to hope for a good death. This keeps the spirit of hope alive while helping the patient and family to focus on living life to the end.

Open communication builds trust when it is facilitated at an age-appropriate level and includes the family as a unit of care. Open communication allows the child or adolescent who is facing a life-threatening or terminal disease to receive the much-needed source of support from medical professionals and their family to face each day with the assurance that they are not alone. Open communication is an integral part of excellent palliative care.

Interdisciplinary Care Across Settings

One of the gaps in the effective provision of pediatric palliative care is coordination of interdisciplinary services across hospital and community settings. When a child or adolescent is hospitalized with a life-threatening or terminal disease, there are many disciplines available to provide care. The medical team consists of physicians of every specialty and nurses specifically trained in pediatrics, along with clinical psychologists, medical social workers, child life specialists, registered dietitians, physical therapists, and pharmacologists trained specifically in the delivery of pediatric medications. There is also a chaplain service available to address the spiritual needs of the individual and family. When the child or adolescent is discharged to their home community, there is sometimes a lapse in the provision of palliative care services. For example, some communities do not have home care services with nurses who are trained to provide complex care in the home environment. Additionally, there is a need for respite care, since the parent(s) become the primary caregivers around the clock. When home care services are available, nurses often assume the role of social worker and counselor to address the psychosocial needs of the child or adolescent and family who are facing a life-threatening illness.

Pediatric palliative care programs that provide coordinated care across hospital and community settings benefit the child or adolescent facing a life-threatening or terminal disease while also benefiting the family unit and the community at large. Programs that unite community-based interventions, medical professionals, and volunteers with a common purpose—to care for the medical, nursing, psychosocial, and spiritual needs of the child and family—can be very fulfilling. Families benefit from added social support, and children and adolescents benefit by remaining comfortable at home. Additionally, such programs could provide financial benefit by reducing the costs associated with multiple hospitalizations.

Shared Decision Making

The final component of quality pediatric palliative care is shared decision making. Advocating for child or adolescent and caregiver (parent) participation in decision making has become increasingly important in today's health care system. Shared decision making allows the child or adolescent and family to actively participate in the decision-making process by being fully informed about treatments, interventions, and clinical trials. Guidelines have been developed that encourage health care providers to share information at a developmentally appropriate level so the child or adolescent can be fully informed and therefore actively participate in decisions about their care. Children and adolescents under the age of 18 are generally not legally given the right to consent or refuse treatment. However, children and adolescents have a moral right to complete and thorough explanations about treatment and procedures that are explained in a developmentally appropriate way. Children and adolescents should be given the right to assent to treatments, interventions, and procedures as young as 7 years of age. Parents are legally responsible for consent to medical procedures until the child or adolescent is of legal age.

Children and adolescents who live with chronic, life-threatening illnesses become socialized to death and dying at a much younger age than their healthy peers. Studies conducted on children or adolescents with life-threatening diseases, such as cystic fibrosis or cancer, confirm that older children and adolescents feel they are not adequately informed of their disease process and treatment options. Conducting family discussions within the context of open communication can help facilitate shared decision making.

The older adolescent (14–19 years old) appears to desire more direct communication and participation in decisions about care. There are some distinct benefits that have been reported in the literature on shared decision making that are worth noting for the older adolescent. Increased information and involvement in decisions may increase coping mechanisms, decrease fear of the unknown, reduce uncertainty and depression, increase sense of control, and enhance self-esteem.

Shared decision making is a by-product of open communication. Respecting the child or adolescent, his or her family, and their unique family culture will foster an environment that promotes the collective desires of the medical team, adolescent or child, and the parent(s). Shared decision making provides quality pediatric

palliative care to the child or adolescent with a life-threatening or terminal illness and his or her family.

Individual and Family Health Outcomes

The purpose of pediatric palliative care is to reduce suffering and improve the quality of living in children and adolescents with life-threatening or terminal illnesses and their families. The focus of individual and family health outcomes is aimed at improving quality of life. Many children and adolescents face years of aggressive treatments aimed at cure. Others have treatments that promote quality of life while coping with chronic diseases over many years. Still others ultimately die from disease progression. Facing death, particularly the untimely death of a child, creates many challenges within the family that can have devastating effects on each family member and thereby threaten the stability of the family unit. Alcoholism, drug dependency, and divorce are a few of the adverse outcomes reported after the death of a child.

Siblings are particularly vulnerable to misunderstandings. Rarely is the sibling included in health care discussions, so the bulk of information a sibling receives is from bits and pieces of information exchanged among adults in the home or hospital setting. Several studies have shown that surviving siblings of all ages have benefited from involvement in the dying process. Siblings need support from a trusted adult to process thoughts and fears related to serious or life-threatening disease and the possibility of death. Surviving siblings cope better with home versus hospital deaths. In addition, open communication between parents and surviving siblings is critical to sibling well-being during the bereavement process. Palliative care that focuses on the family as a unit considers health outcomes that are important for each family member. Grief adjustment and perceived social support are important health outcomes for siblings.

Health outcomes aimed at improving quality of life for parents include grief adjustment, perceived social support, and secure interpersonal relationships. Parents, who generally provide stability for the home, experience a tremendous emotional toll. They juggle the responsibilities of caring for a seriously ill child while raising a healthy family. Many times, one parent stops working to care for the ill child. Frequent hospitalizations can also separate the family unit and add to the financial strain. Financial and caregiver stress sometimes negatively impact marriage relationships, parenting, employment, and social relationships. Each of these factors contributes a threat to the stability of the family unit. Community and social support are needed to keep the family unit intact.

Individual health outcomes for the child or adolescent facing a life-threatening or terminal disease include perceived social support, improved quality-of-life outcomes, preparation for advanced disease or death, symptom control, reduced distress (physical, psychological, or spiritual), and access to quality services and support across community settings. Pediatric palliative care embraces not only the child or adolescent with a life-threatening disease but also the family unit consisting of parents and siblings. Extended family members, such as grandparents, are often intimately involved in providing tangible support during this crucial time of need.

Pediatric Palliative Care Interventions and Programs

There are several pediatric palliative care initiatives that have been developed to address the family-centered and health care provider educational needs. Each program or educational intervention is briefly discussed in this section.

The Initiative for Pediatric Palliative Care (IPPC) is both an education and quality improvement effort whose purpose is to enhance family-centered care for children with life-threatening conditions. By collaborating with pediatric hospitals and children's hospices and home care agencies, IPPC provides curriculum and support to implement skills in local health care facilities. More information is available at the IPPC website.

The goal of Children's Project on Palliative/Hospice Services (ChiPPS) is to enhance the science and practice of

pediatric palliative care and to make readily available the best practices of pediatric palliative care to health care providers. Through the collaborative efforts of the National Hospice and Palliative Care Organization (NHPCO) and pediatric experts in palliative care, the ChiPPS program was developed. To find out more about ChiPPS, visit the NHPCO website. It provides educational resources and recommended children's books on grief and loss. In addition, there are links to organizations such as Partnering for Children and the Children's Hospice and Palliative Care Coalition.

The End-of-Life Nursing Education Consortium (ELNEC) Pediatric Palliative Care Program provides the educational curriculum to train nurses in pediatric end-of-life care. ELNEC offers train-the-trainer programs so that nurses who receive training can return to their hospital or institution to provide local training with ELNEC educational resources. For more information on ELNEC training, visit the American Association of Colleges of Nursing website.

Children's Hospice International Program for All-Inclusive Care for Children and their Families (CHI-PACC) is a model of care aimed at providing a continuum of care for children and their families across hospital and community settings. One of the goals of CHI-PACC is to provide appropriate pediatric palliative care services in the preferred location of the family rather than in the setting that is dictated by a payer source. For more information on the CHI-PACC program, visit the Children's Hospice International website.

Centers for Grieving Children exist in several cities with programs to help the surviving siblings. In 1982, the Dougy Center was started as the first U.S. organization to provide peer support groups for grieving children. Today, there are many programs named in honor of a child who taught others the importance of living, such as Erin's House for Grieving Children, Judi's House, Gerald's House, and Brooke's Place, to name a few. Services are generally free and provide support for as long as the service is needed from several months to years after the death of a loved one. The Dougy Center provides a link to more than 500 centers that provide grief counseling and services nationwide—the link on the Grief Support Resources page of the Dougy Center website is searchable by city, state, or zip code.

Relevance of Pediatric Palliative Care to Broader Health Issues

A child's death can have a devastating effect on members of the community. It is estimated that each child impacts 300 people, from hospital personnel to school officials and classmates, neighbors, friends, family, and those who attend church, mosque, or synagogue together. The death of a child defies the natural order of life events. People young and old are left to process the pain of separation with questions that may never be answered. Effective pediatric palliative care programs strive to support the family as a functioning unit of care from the point of diagnosis throughout the course of disease to either a cure or end of life. Bereavement follow-up in pediatric palliative care is not common practice. Few acute care settings, such as hospitals, have the time or resources to provide a formal bereavement program to support families and friends through the initial year of anguish after the death of a child. This is a particularly vulnerable time for the family. Although there are resources available in most communities, families may not be aware of, or have the wherewithal to access, organizations that provide such services. Lack of resources or support can lead to complicated grief and breakdown within the family. Perhaps the answer is collaboration. Hospitals and agencies willing to partner together may provide the necessary community support to deliver comprehensive pediatric palliative care and support the healthy functioning of the family unit.

—Cynthia J. Bell

Further Readings

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