

A Call for Change:
Recommendations to Improve the Care of Children Living with
Life-Threatening Conditions

**A white paper produced by the Children's International Project on Palliative/Hospice Services
(ChIPPS) Administrative/Policy Workgroup of the
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Purpose of the document

Infants and children die — some from conditions with which they are born, others tragically from accidents, trauma or illnesses. Chronic illness and death can result in devastating consequences for affected children and the people who know and love them, but these consequences are not a foregone conclusion — the harm associated with the death of a child can be lessened by the provision of palliative and bereavement care.

Palliative care is the science and art of lessening physical, psychosocial, emotional and existential suffering. Palliative care can benefit patients and families whether the overall goals of care are to cure, prolong life, maximize the quality of the life that remains or ease the pain of bereavement. Thus, palliative care may be provided concurrently with, or as an alternative to, life-sustaining medical intervention. Palliative care addresses not only the patient, but also the family and community who care for and about the patient. A palliative care knowledge-base exists that can substantially improve the experience of children living with life-threatening conditions and their families. However, because this knowledge is not widely taught in health professions' training programs, and in part because it is care that is currently unpaid, pediatric palliative care is not widely available.

A multidisciplinary group of experts in pediatric palliative care undertook a literature review in 1999-2000, documenting what is known about programs of care for children living with life-threatening conditions — what is helpful and efficient; what is not necessary; what does NOT work; and what is unknown. Some information was extrapolated from developmentally disabled or demented adult populations, but extreme efforts were made to review pediatric-specific literature, ranging from premature infants to mature young adults. The broad and varied experiences of this group were then applied to this published information, resulting in a recommended template for pediatric palliative care programs.

This document identifies actions that legislators, regulators and administrators dedicated to the welfare of children can take to improve the experiences of children living with life-threatening conditions and their families.

Legislators, regulators and administrators need to know:

- 1. How to identify families with children who can benefit from palliative care (i.e., children living with life-threatening conditions (LWLTC));**
- 2. The spectrum of needs of children LWLTC, their families and communities, both during the child's life and after the child's death;**
- 3. What a program that will effectively meet the needs of this population in a cost-efficient manner looks like and how to build on existing successful programs and models of care;**
- 4. How to measure the success of palliative care in meeting the needs of children LWLTC and their families;**
- 5. How to address the need for educational opportunities and research in pediatric palliative care; and**
- 6. The estimated costs of such a program of care.**

Executive Summary and Recommendations

Approximately 400,000 American children live every day with chronic, life-threatening conditions.^{1,2,3,4} Approximately 53,000 children die annually; half of these children die acute traumatic deaths, deaths related to profound birth defects or sudden infant death syndrome (SIDS), while the remainder die of chronic, sometimes life-long disorders.⁵ Estimates of the prevalence of children living with life-threatening conditions are similar in the United Kingdom, with estimates ranging from 1:1000⁶ to 1.72:1000 children⁷, the higher numbers being more recent, and perhaps more accurate, as greater case-finding efforts are made.

Currently, only about 5,000 of the 53,000 dying children receive hospice services, generally for a brief duration. Delayed implementation of palliative care interferes with the all-important focus on prevention of unnecessary pain and other symptoms, effective communication, preparation for death, and orchestration of care to achieve the child's and family's goals. Early identification of children who are LWLTC is an important priority to enable prompt access to palliative care.

Interventions needed to realize the potential benefits of palliative care include extensive counseling by physicians, nurses, psychologists, social workers, spiritual counselors, allied health therapists, volunteers, and respite care workers/sitters trained in pediatric-specific palliative care.

Palliative care services must be designed to meet the longitudinal needs of children who die and their families, whether the child dies acutely of trauma, or of a more chronic process or condition.

Pediatric palliative care services must be available in the home, acute care hospital, and in any other setting in which the family and child feel comfortable.

Palliative care services for children will only be available when there are personnel educated and trained in the provision of pediatric palliative care.

Palliative care services for children will only be widely available to when reimbursed equitably.

We estimate a total national expenditure of approximately \$630 million annually (compared to \$1.1 trillion of national expenditure on healthcare costs in the U.S. annually) to provide effective palliative care for the population of children who die. Other alternative costs of care for these children will decrease, the number of hospital bed days will be reduced and, **most importantly**, patient and family outcomes will improve.

Most hospice programs are inadequate in their present structure and reimbursement mechanisms to meet the needs of children LWLTC and their families. Late referral, increased medical expenditures compared to adult hospice patients, limited availability of programs with personnel trained in pediatric palliative care, and prolonged bereavement care costs are significant barriers.

Access to respite care, a vital service, is limited by a general lack of available services, reimbursement, and family confidence in the care providers. Training programs for respite caregivers and wider care options are important remedies for this problem.

Research in pediatric palliative care is lacking, and dedicated research funding will create the evidence-base that will drive improvement in care and education.

Recommendations

Clinical Issues

- The sole admission criterion for pediatric palliative care services must be that the child is not predicted to survive to adulthood. Prognosis for short-term survival cannot be required; death of a child is very difficult to predict, and this criterion interferes with access to palliative care.
- Reimbursement patterns must be changed to reflect the value of comprehensive care for children LWLTC, including excellent communication and counseling; effective, efficient pain and symptom management; coordinated, seamless care between settings and healthcare episodes; and grief and bereavement support for the child and family.
- Interdisciplinary care team meetings are critically important to proper management of the illness, associated physical symptoms, and psychosocial and spiritual issues.
- Families should have unlimited access to their children, regardless of setting.
- The use of the school as an expensive and inefficient *de facto* respite provider should be revisited.
- Providers who care for children living with and dying from life-threatening conditions encounter losses and may experience stress; provision of support for staff should be a mandatory component of pediatric palliative care services. Reimbursement for expenses should factor in an allowance for the above-referenced services.
- Hospice or independent grief counselors should be available to consult with or be employed by hospitals. Post-death care for families and medical care providers should be included in programmatic healthcare design and funding.
- Provision of support services to teacher(s), schoolmates and members of community organizations affected by a child's critical illness and death is compassionate, reasoned, and cost-efficient.

Education Issues

- There are currently very few providers of any discipline that are familiar with pediatric palliative care. **The need for education is urgent.** Thus, financial incentives for training in pediatric palliative care must be made available. Tuition sponsorship and discounted liability coverage or bonuses are options to consider. Institutions that make palliative care a priority should receive tangible assistance.
- Sufficient resources must be allocated for the development and implementation of innovative training programs in palliative care in schools of medicine, nursing, and social work. Minimal standards for program content and competency-based testing must be developed.
- Appropriate faculty expertise, time and resources must be mandated to address pediatric palliative care issues. Health professions schools must commit to having qualified faculty experienced in palliative care and supportive services available.

- Pediatric residency and subspecialty fellowship programs must incorporate pediatric-specific palliative care information. Continuing education programs and certification will rapidly make urgently needed pediatric palliative care more available and accessible.
- Training in pediatric palliative care for home care and hospice workers, nonprofessional caregivers, parent aides, and volunteers must be provided to enable competent care for children LWLTC, particularly in the terminal phase.
- Counselors, psychologists, schoolteachers and officials need training to effectively accommodate the needs of terminally ill children and their classmates.

Legal/Ethical Issues

- Good Samaritan legislation must be enacted to enable parent-to-parent networking and respite cooperatives referral by healthcare institutions and individuals.
- The concept of pediatric assent should be actively taught and embraced in policy and law. Extending the mature minor doctrine to children with capacity for medical decision-making, regardless of age, should be supported in state, institutional and reimbursement policies. Development of tools to assess minors' capacity to participate in decision-making is desperately needed.
- Orders to forgo resuscitative efforts (DNR) outside of hospitals must be honored in school and other public and non-hospital settings, including the emergency medical system.

Research

- Adequate funding for research in pediatric palliative care must be allocated. Only then will children and families be assured that they are receiving proven therapies. Outcome measures relevant to the child and family must be developed. Continued extrapolation from adult data is unethical; it has been shown repeatedly that children are not small adults — physically, psychologically, emotionally or otherwise. Research applied to children must be derived from children and their families. Research should build on evidence that already exists, be innovative, and fill existing gaps in knowledge and applied practice.
 - Specific and urgent research issues include the early identification of children who can benefit from palliative care; the utility of care coordinators to orchestrate the care of the child; the effectiveness of parent education tools to ensure informed consent; the effectiveness of sibling interventions to improve bereavement outcomes; and the safety and effectiveness of treatment and prevention of pain and other symptoms.
 - Tools to assess the quality of and satisfaction with pediatric palliative care must be developed and tested.
 - The associated costs of palliative care interventions must also be tracked.
- Standards for the provision and reimbursement of pediatric palliative care services need further development and need to be integrated into the larger healthcare system.

Introduction

There has been an increased realization that we have been inadequate as a society and as a healthcare community in addressing the needs of the terminally ill.⁸ Discussion thus far has emphasized care of dying adults, particularly the elderly. While the number of children who die in the U.S. annually is dwarfed by adult deaths, the number of lives affected by the death of a child is considerable. The impact of a child's chronic illness and death on parents, siblings and friends is profound. Improved palliative care for children must become a priority of our society and our healthcare system.^{9,10}

The American Academy of Pediatrics (AAP) is calling for improvements in the care of children living with life-threatening conditions in its guideline "Palliative Care for Children."¹¹ The AAP delineates a broad outline of changes needed to facilitate such improvements, including:

1. Programs that offer elements of palliative care from the time of diagnosis of a potentially life-threatening condition;
2. Availability of palliative care concurrently and intimately intertwined with life-prolonging care;
3. Improved regulation and reimbursement for palliative care services;
4. Widespread availability of respite care (relief for families who care for their child);
5. Improved support of family and professional caregivers; and
6. Improved research and education, enabling professional caregivers to provide effective and cost-efficient care to children living with life-limiting and life-threatening conditions.

This document provides concrete guidance to achieve these goals.

Who Are the Children Needing Palliative Care? A case example

Jessica, a 16-year-old girl with leukemia, has undergone extensive and uncomfortable, isolating, and sometimes painful treatment for her cancer. She is in the hospital with her fourth relapse, commonly a harbinger of death. Jessica's physician does not feel comfortable addressing her prognosis with either Jessica or her family, nor the advisability of changing the primary goals of treatment from attempts to cure to attempts to maximize the quality of her remaining life. He has received no formal training on how to conduct such a conversation, despite 10 years of medical training. In addition, he will not be reimbursed for the time it takes to have this *series* of painful, difficult and lengthy discussions. Budget constraints and limited educational opportunities constrain the availability of social workers, child life therapists, nurses and pastoral care workers with pediatric expertise as well. As a result, discussions regarding Jessica's priorities do not take place. Jessica, predictably, becomes critically ill. Rather than going home to be cared for in a familiar and comfortable setting, as she may have preferred, she is transferred to the intensive care unit (ICU). She undergoes CPR, among other therapies with no realistic hope of prolonging her life or promoting her comfort. In the meantime, her mother, unprepared for her death, waits outside the ICU door, refusing to "give permission" for this futile care to stop. Nevertheless, Jessica dies. In less than 12 hours, well over \$3,000 has been spent on care without demonstrable benefit, and some would say care that even caused harm, for Jessica and her family. The ICU and oncology staffs are demoralized. No mechanism exists for bereavement care of the family or staff.

The resources spent in this scenario could have produced much greater benefit. Palliative care, including counseling and pain and symptom management, could have been provided over the course of weeks or months, allowing Jessica, her family, and her caregivers the opportunity to enjoy an improved quality of life while she received care directed at cure. When curative goals became elusive, increased attention could have been focused on celebrating relationships, preventing unnecessary symptoms, and ensuring effective communication. Palliative care enables the accomplishment of final goals, as well as the achievement of some degree of acceptance and peace if death is the final outcome. Bereavement support for surviving family, friends and professional caregivers is part of palliative care.

Identification and Demographics of Children Living with Chronic, Life-Limiting Conditions

There are 78 million children aged 0-19 in the U.S. Eighteen percent suffer from a chronic health condition that compromises the child's quality of life (e.g., asthma).¹² It is difficult to obtain clear estimates of how many of these children can benefit from palliative care; certainly not all. Using severity of illness ratings employed by the National Association of Children's Hospitals and Related Institutions (NACHRI), approximately 1.9% of 0-17-year-olds have major (S3) to extreme (S4) levels of disability that would likely qualify them for palliative care services.¹³ Of these, 446,000 (0.7%) are unable to conduct age-appropriate activities, including 92,000 (0.14%) children who are institutionalized.³ Similar demographics of chronic and terminal illness among children in the United Kingdom have been published.¹⁴ In the U.K., estimates are that 1:10,000 children die annually of chronic conditions and 1:1000 children live with chronic, life-limiting conditions. Several recent articles and statewide efforts have accumulated ICD9 Codes that track well with child mortality statistics.^{3,4,13,15,16} It is more difficult to identify children who are chronically ill and destined to die during childhood. It is the group of 446,000 children, as well as similar children around the world who are addressed in this paper.

Cause and Location of Childhood Death

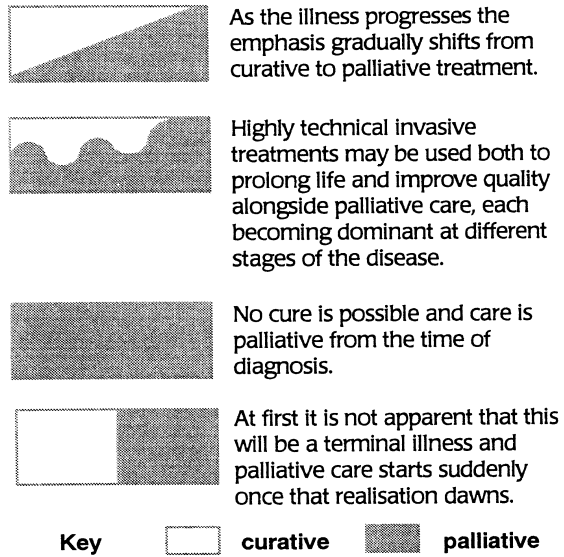
Each year, approximately 53,000 American children (0-19 years of age) die.⁵ Infants (children under 12 months of age) account for half these childhood deaths. Infants die of prematurity, congenital defects, and rare disorders. With overwhelming frequency, these children die in the hospital. Most infants die in an ICU setting, but with wider availability of palliative care support, many could have the option to be cared for at home.^{17,18} Increasingly, infants are dying of chronic conditions; 41% of infant deaths resulted from chronic conditions in 1997 compared to 31% in 1980.⁴ These children need longer-term palliative care with home-based options. New research on symptom control for these children, given their unique physiology and symptom complexes, is vital.

Children (aged 1-19 years) account for 26,000 U.S. deaths annually; 36% die of congenital and chronic conditions, including cancer. These children could also benefit from long-term palliative care. The remaining 64% succumb to trauma, including accidents, suicide and homicide.¹⁹ Children who die acutely, their parents and siblings, can also benefit from attention to their physical, spiritual and emotional needs. Seventy-five - 85% of deaths among children aged 1-19 occur in the hospital, three-fourths in tertiary care hospitals, often far from home.^{17,18} Some of the chronically and ultimately terminally ill children can be better served at home. However, the causes of childhood death ensure that the majority of children who are dying will continue, inevitably and appropriately, to be cared for in the acute care setting. Pediatric palliative care services must therefore be available in the home, acute care hospital, and in any other setting in which the family and child feel comfortable.²⁰

In total, approximately 8,600 children on any given day would need palliative care services, based on an "intensive" daily level of need of 90 days' duration for the chronically ill infant and 180 days for the chronically ill child prior to death. An article by Feudtner, Christakis and Connell is helpful in delineating the usual age of death, and thus duration of service, for the chronically ill child population.⁴ Some chronically ill children need only intermittent services, such as a routine monthly visit, with an increased frequency of visits during periods of crisis. Acutely injured children generally require intensive services for 1-7 days prior to death. Their needs are very labor-intensive on the day(s) of injury and death. In addition, their families require long-term bereavement care, a service not reimbursed under most hospice benefit plans.

IN MEETING THE COMPREHENSIVE AND LONGITUDINAL NEEDS OF CHILDREN LWLTC OR DYING ACUTELY AND THEIR FAMILIES, OUR NATION WILL NOT INCUR MASSIVE COSTS. We estimate a total national annual expenditure of approximately \$630 million to provide effective palliative care and end-of-life services for children. This estimate includes the range of causes of childhood death: 11,890 infants dying of chronic conditions; 9,360 children aged 1-19 years who die from chronic conditions; 4,160 children dying of traumatic injury, and a daily, rotating group of 1,000 terminally and chronically ill infants and children who need intermittent services to maintain or maximize quality of life. We base our estimate on a cost of approximately \$200/day for palliative/hospice care. This \$630 million does not represent new spending, but a more effective allocation of services, better meeting the needs of the children and their families. The actual costs and cost-savings from redirecting care to better meet the needs of these children and their families awaits further, more sophisticated, prospective analysis.

Curative and Palliative Care Relationship



Report of a Joint Working Party of the Association for Children with Life-Threatening or Terminal Conditions and their Families and the Royal College of Paediatrics and Child Health. A Guide to the Development of Children's Palliative Care Services, 1997, Bristol.

The above diagram illustrates the common trajectories of pediatric death, highlighting the different needs of these children and their families, as well as the difficulties in identification of such children.

What Makes Pediatric Palliative Care Challenging?

1. Our society does not expect children to die.
2. Families often believe medicine can currently or imminently cure all ills.
3. There is a huge disparity in Western countries in resource allocation, favoring “cure-oriented” acute care interventions over palliative care.
4. Death is inherently a social/community event, not a medical event. At the present time, it is placed in the hands of a medical community ill-prepared to meet these unique needs, particularly for children, who frequently die in the hospital.
5. Determining prognosis and estimating time of death for children with neurologic compromise, rare diagnoses, and other common causes of pediatric death is an inherently uncertain process, representing a barrier to palliative care if estimated survival time is a criterion for eligibility to receive palliative or hospice services.
6. Determining goals of care and fashioning an acceptable plan of action are extremely time-consuming and poorly reimbursed, whether the provider is explaining “life-prolonging” or palliative measures. It is these lengthy and recurrent explanations that enable truly informed consent, emotional peace, and care plans consistent with the goals and philosophy of the patient and family.

7. There is a misperception among healthcare professionals, legislators, administrators and the general public that palliative care is only of use when all curative efforts have been exhausted and that it is mutually exclusive with life-prolonging care.
8. Variation in the cognitive, emotional and social development of the child affects communication and decisional capacities. Determining the best interests of a child with unknown current and future values is difficult for families and professionals.
9. Very few individual practitioners are highly experienced in guiding decision-making with or caring for dying children and their families.
10. Poor communication, guilt, and societal expectations, often force children endure therapies that adults, given the choice, reject for themselves. Families willing to forgo life-prolonging therapy are at risk of being accused of not caring about their child.
11. Obligations to the child-patient and family may be conflicting, and difficult for healthcare professionals to resolve.
12. Current regulations may interfere with family/patient-centered decision-making.

Current Pediatric Palliative Care Service Models

The application of palliative care principles improves the ability of the child to carry on his or her normal activities with minimal discomfort, whether or not disease-modifying treatment is being received. Quality of life should be family-directed and should serve as the guiding principle in determining the plan of care throughout chronic illness.^{9,21,22,23,24,25,26,27,28,29,30,31,32,33,34,35}

Providing comprehensive, individualized palliative, respite and end-of-life care services for patients and their families presents a significant challenge to healthcare providers and social support systems. Care for children with chronic, life-threatening conditions involves multiple clinic appointments, developmental services, complex home medical treatments, and occasional acute deteriorations, at times requiring 24-hour home-based or hospital care. Parents may lose their jobs and insurance in trying to meet their child's needs. The family may then become uninsurable because of the child's pre-existing condition. In this and a multitude of other ways, the child's illness impacts all family members.³⁶

Financial and community resources are currently inadequate to meet families' needs. Financial ruin is not uncommon. Families incur substantial indirect costs when caring for their chronically or terminally ill child; in one report, the incidental and indirect costs averaged \$140 per week,³⁷ including loss of wages or employment, the need for babysitters for siblings during the patient's hospital and clinic time, and need for assistance with transportation. There are also costs associated with the need for special diets for the sick child, linens, equipment, alterations to the home to adapt to the child's disability, bath supplies, and non-prescription medications, none of which are covered by medical insurance.

The only widely available systematic approach to life-threatening illness in the United States at the present time is hospice care. Hospice care is comprehensive, all-inclusive care addressing the physical, psychosocial, emotional and spiritual needs of the patient who is acknowledged to be dying and his or her family. It is reimbursed as a per diem, all-inclusive package, at an average of \$107 per day. Current federal eligibility guidelines for the Medicare hospice benefit, which was designed for adults, but is often (inappropriately) applied to children by payers, require the physician to certify and the patient or surrogate to agree that the patient will die in the next 6 months. Hospice care is therefore generally confined to patients of any age who no longer value the prolongation of life, are easily accommodated in the home setting, and do not have intensive or expensive care needs. Moreover, while 93% of hospice programs will admit a child, many do so on a case-by-case basis, using qualified adult hospice personnel with little to no pediatric experience. It is difficult for families, pediatric health professionals and hospice providers to feel comfortable with this arrangement, creating yet other barriers to hospice or palliative care for children in the United States. Fewer than 10% of the nation's 3,100 hospices have dedicated pediatric palliative care services. On the other hand, one well-known Canadian program, Canuck Place in Vancouver, provides care by pediatric nurses and other care providers for children with life-threatening conditions, often providing intermittent respite care over the course of years, as well as providing more intensive symptom management in the facility and providing advice and/or direct care at the child's home. In the United Kingdom, a country the size of Virginia, there are 23 children's inpatient hospices and a network of specially trained pediatric nurses and other community-based pediatric providers. In addition, there is a centralized education and backup system for the child's uncontrolled symptoms, available 24 hours a day. The admission criterion for the U.K. programs is that the child is not expected to survive to become an adult; concurrent life-prolonging and respite care is a large part of the activity of the programs.

Cure is never a possibility for many chronically ill children destined to die during childhood; however, this does not preclude the value of continued life. The critical issue is maximizing quality of life for affected children and families, a goal that is difficult to achieve if access to expertise in physical symptom management and psychological counseling is restricted. In addition, families whose child dies acutely or unexpectedly from trauma currently have no mechanism to access caregivers with expertise in palliative care, grief and loss.

Some larger hospices with home health licenses as well as hospice licenses are able to provide palliative care to children seamlessly from the time of diagnosis, providing the continuity of care necessary for the well-being of the child and family. Examples include Hospice Atlanta, Hospice of the Florida Suncoast, Hospice and Palliative Care Center in Buffalo and San Diego Hospice. Some services can be billed “fee-for-service” under a home health license, increasing care as the intensity of need increases and reducing care if needs decrease. Smaller hospices, often the sole providers in rural areas, are unable to secure the expensive home health license that enables such a model. Much of the care provided currently goes un-reimbursed, as it is deemed not “medically necessary”; this includes pastoral counseling, child life care for improving communication with children and siblings, massage for pain relief, care coordination, as well as other critical services. This disincentive guarantees the lack of appropriate services. Thus, hospices operate in deficit when serving the needs of a child.

Current federal and state regulations discourage hospices without home health licenses from providing palliative care before the terminal phase is certain, implying that hospices are inappropriately “soliciting business” by caring for “pre-hospice” patients. The result is to limit the number of available programs, confining children and families who may want to go home, particularly those living in rural areas, to the hospital, incurring unnecessary, often extraordinary, costs. Remaining in the hospital increases the risk of unwanted medical testing and intervention, and is burdensome emotionally, physically and financially to the child, family and society.

When children are admitted as hospice patients, with a prognosis for survival of 6 months or less, their care needs often far exceed the average \$107 hospice per diem allocation. The per diem is expected to cover professional services, diagnostic and therapeutic interventions (medications, transfusions, etc.) and durable medical equipment rental or purchase (hospital beds, oxygen, ventilator). The Medicare regulations require a minimum 1 year of bereavement follow-up, but this is specifically non-reimbursed. The shorter the hospice length of stay, the more intensive the bereavement needs often become. The few children who are currently enrolled in hospice are often enrolled only during the last few days of their lives due to typical causes of pediatric death, associated uncertainty of prognosis, psychological difficulty for families of forgoing life-prolonging care,³⁸ and reluctance of professional caregivers and/or family to acknowledge the impending death of a child. Smaller hospices in particular are thus reluctant to admit children. However, hospices typically possess rare community-based expertise in grief and loss. Creating a mechanism for hospice or independent grief counselors to consult with or be employed by hospitals could help. If grief counseling and bereavement services were billable, they would be more readily available.

In summary, hospice programs are inadequate in their present structure and reimbursement mechanisms to meet the needs of children LWLTC and their families. Late referral, increased medical expenditures compared to adult hospice patients, lack of pediatric expertise, and prolonged bereavement care costs are significant barriers.

If the child qualifies for Medicaid and the state has a Medicaid waiver program for children LWLTC, some form of palliative care services may be available. Some Medicaid waiver programs have case

managers to provide consistency and continuity of care. However, the majority of these programs are restricted to patients who would otherwise be institutionalized or are technologically dependent (a small but costly subpopulation of the children LWLTC). Such admission criteria prevent access to the program for the majority of children and families who benefit from them.

Particularly within the hospital, palliative care is often unavailable. Only the largest 5%³⁹ of hospices can accommodate an inpatient consultation team or an urgent care/in-hospital response team, again because this care is currently totally un-reimbursed. Separate from the issue of hospices serving hospitals is the concept of the hospital itself addressing the palliative care needs of their patients. Forty-eight percent of pediatric oncologists report palliative care teams are rarely or never available, and 30% of oncologists state that pain teams are sometimes, rarely, or never available in their inpatient settings.⁴⁰

Since so many children die in the hospital,¹⁸ palliative and hospice care services currently are effectively out of reach for the majority of children and families who could benefit. Acute trauma victims and small premature infants will inevitably die in the emergency room or ICU setting. Infants born critically ill may never have the opportunity to leave the hospital. Urgently available, intensive palliative care will thus always be necessary. Palliative care services must be designed to meet needs across the spectrum, accommodating acutely dying children, children dependent on ICU technology, and the chronically terminally ill child.

When the child is hospitalized during his or her final days of life, barriers to achieving optimal outcomes for patients and families include rigidity of hospital rules and policies, and limitations of physical space for the delivery of care. Separate, larger rooms or multi-bed family units where families are able and encouraged to provide physical, spiritual, cultural and emotional comfort to the child and each other have been shown to be effective in minimizing stress, and enable families to provide a more meaningful experience for their dying family member. Programs utilizing such physical space and employing practices to promote quality end-of-life care to the child and family taken as the irreducible “unit” of care have demonstrated positive outcomes.⁴¹

Even in the high-tech surroundings of an ICU or emergency ward, the death of a child can be made more humane and have enormous consequences on the long-term functioning of families. The physical presence of the family during ICU stays or emergency room resuscitation efforts and the opportunity to spend time with the deceased child’s body are helpful interventions, enhancing the ability to cope with sudden and tragic loss.⁴²

Family-centered institutional behaviors minimize complications of bereavement and decrease physical manifestations of grief. “Somatic” or bodily symptoms of bereaved individuals often lead to visits to medical providers, costly and invasive diagnostic procedures, and absences from work and/or school. Improved outcomes for the bereaved family members should be important goals of an effective family-centered pediatric palliative care program. Enabling reintegration of families into the workforce and into society as quickly as possible requires changes in institutional philosophy and physical layout (e.g., grief rooms routinely available in emergency rooms, a mechanism for prolonged bereavement support). Supportive interventions can free families from regret and guilt for not having done things differently prior to their child’s death. Pediatric staff with expertise in palliative, acute, chronic and bereavement care are mandatory for the achievement of positive outcomes for the families of children who die.

Post-death communication with families during post-mortem or post-autopsy conferences, hospital memorial services and follow-up bereavement phone calls and cards, have been proven to be effective in promoting resolution of grief. Contact by healthcare staff who cared for the deceased child personalizes the loss for families and facilitates improved coping skills.⁴³ While such communication efforts are considered an integral component of a palliative care program, any activities of this nature are currently provided during the free time and out of the good will of the professionals. It is for this reason that many families are deprived of such essential services; professionals who provide such support are not able to sustain the effort for long. It is our recommendation that post-death care be included in programmatic design, with funding allocated that enables staff to routinely engage in such activities.

In today's healthcare market, services are seldom provided when insufficient or no reimbursement exists. Third-party insurers are not held to universal standards dictating the level of palliative and hospice services that must be available. Uncomfortable, invasive and expensive interventions that do not measurably improve survival or quality of life are reimbursed in acute care settings without question. However, palliative care interventions, which may include prolonged and recurrent counseling, pharmacologic and non-pharmacologic methods of pain and symptom management, child life therapy, and pastoral care, are either not reimbursed at all or partial payment is provided, the latter after significant time invested in negotiating payment. This administrative effort is another costly, unreimbursed expense. Institutions attempting to provide appropriate services are limited in their efforts by these financial issues. Reimbursement patterns must be changed to place value on comprehensive care for children with chronic and terminal conditions, including excellent communication and counseling, and relief of suffering for the child and family.

Effective communication is vital throughout the lifetime of a child living with a chronic and terminal condition.. At the time of diagnosis, patients and families need direct, consistent, uninterrupted discussion in a private atmosphere. Information will need to be repeated and clarified at numerous subsequent visits.⁴⁴ The AAP emphasizes the importance of early discussion with families to determine family values, assumptions and preferences regarding treatment.¹¹ Clearly, these discussions require expert medical knowledge and counseling skills, as well as a significant investment of time.

While informed and counseled parents are the child's preferred informants, disclosing difficult news and care options may be too overwhelming a task for them.⁴⁵ Again, special expertise, incorporating attention to the child's developmental and cognitive level of understanding are critical components of ethical care of children, particularly those living with life-threatening conditions.⁴⁶ However, these conversations, currently poorly reimbursed and emotionally trying, do not always occur. Not including the child in decision-making is widely noted to create additional behavioral, social and spiritual care problems for the child and family.

One of the greatest barriers to effective palliative care is lack of communication. More responsive palliative care would be accessible with a model of shared decision-making. Such a model would embrace the following tenets:

1. Clear goals of care are elicited in a shared decision-making process, using the language of the family.
2. Uncertainty of prognostication is disclosed to the family by the managing healthcare team in a manner the family is able to understand; understanding is demonstrated.

3. A clear rationale for the recommendations for care is effectively communicated to the family and child, and is documented.
4. Disclosure of medical facts and value-laden recommendations to the affected child is conducted in a developmentally sensitive manner, with family and other supportive persons present.
5. Goals of medical care decisions are determined by parents, their children (to the extent they are developmentally and physically able and willing to participate), and the healthcare team.
6. Best interests of infants and other young children should be determined with parents. Their assessment should generally be determinative, recognizing that the child's best interests are substantially affected by the family context.
7. Plurality of cultural and religious values is recognized and accommodated.
8. The only treatment options explored should be those which are medically and ethically appropriate options.

Legal and academic changes needed to ensure that these ideals are more routinely employed include:

1. The concept of pediatric assent should be actively taught, embraced in policy and upheld by law.
2. Extending the mature minor doctrine to children with capacity for medical decision-making regardless of age should be supported in state, institutional and reimbursement policies.

Unmet needs

Continuity of Care/Information Gaps

Chronically ill children LWLTC are often cared for by a number of healthcare providers and across a variety of settings, including clinics, inpatient units, home and school. In the absence of clinical leadership across care settings and effective interdisciplinary communication, providers may have conflicting therapeutic goals, placing unnecessary burdens on these children and their families. Pain and suffering is increased in a setting without physician leadership.⁴⁷ The team of caregivers, including the patient and family, can prevent this situation by discussing the goals of treatment together, and fashioning a comprehensive, understandable, coordinated and appropriate plan of care. Interdisciplinary care meetings, a personnel-intensive and currently un-reimbursed component of care, are the key to achieving this ideal. It is also necessary to ensure the child has a case manager and an updated, portable written care plan. A member of the team must be available to the family 24 hours a day, seven days a week.

Respite Care

Parents of children LWLTC become healthcare provider, mental health counselor, spiritual counselor, home health aide, and lastly, parent, spouse and employee. They perform roles for which they receive little or no training and no payment, in order to avoid institutionalizing or abandoning their child. Respite is defined as the provision of care, for the ill child by alternate care providers, rather than the parents, when a child is “medically stable” (i.e., in his usual state of health), enabling time off from the exhausting care these children require. Parents of children LWLTC need time and energy to tend to their own basic physical and emotional needs and to be available to care for the other members of their family. Small breaks are rejuvenating, enabling parents to enthusiastically resume caring for their sick child, improving the child’s care, the quality of life, and the ultimate bereavement outcome for the whole family. Enabling parents to carry on by providing respite substantially decreases costs, monetary and otherwise, to society.

Respite care can be provided in the home by a trained professional, family member, volunteer, or paid sitter. Out-of-home respite can be provided by hospital units, residential facilities such as nursing homes, licensed foster parent respite care or medical daycare programs. An excellent review of respite care models is a 1979 staff paper, “Overview of Respite Care Programs,” presented to the West Michigan Mental Health and Mental Retardation Planning Section, December 12, 1979, study # 80-6.⁴⁸ Access to respite care is limited by a general lack of available services.⁴⁹ Instead of receiving respite care, many severely neurologically disabled and even technology-dependent children are sent “to school,” unfairly burdening school systems with the inefficient use of 1:1 nursing for some children who are unable to interact with their environments, recognize usual caregivers, or benefit from an educational program. Alternatives may also need to be explored for other groups of children who can potentially be cared for together by a single nurse while at school.

Parents are reluctant to utilize respite services because of concern regarding the qualifications and competence of the caregivers. Out-of-home respite, provided in the U.S. in hospitals and nursing homes that serve adults, is frequently not desired by parents. Nursing homes are not usually equipped or trained to care for children. Medical daycare is an infrequently available alternative for children who do not benefit from the intellectual and emotional stimulation of school. Where it is available, payment for respite care can sometimes be made on a sliding scale. In Florida, medical daycare costs \$160.05/day for up to 12 hours of care; Medicaid pays for this, but private insurers do not.

In the United Kingdom, dedicated Pediatric Hospice Homes staffed by pediatric caregivers, nurses and doctors with palliative care expertise have been extraordinarily popular; 24 programs now exist. Activities and therapies are tailored to children LWLTC. The U.K. programs provide continuity of care in the community, in addition to working with the referring hospital to provide a smooth transition between settings.

A parent-to-parent cooperative is probably the most cost-effective form of respite. It meets a broad spectrum of needs for the group of chronically ill children with “stable” medical problems who do not require complicated equipment that would interfere with transportation. Parent-to-parent cooperatives allow parents of children with similar medical conditions and needs to band together to form a network of support for each other, including respite care services, with no additional out-of-pocket expenses. This model was successfully utilized in Michigan, as detailed in the report referenced above. A coordinator designs, develops, manages and evaluates the program,

providing a procedural manual and parent handbook. The keys to enabling parent-to-parent respite co-ops are to:

- Have a written plan of care.
- Enact Good Samaritan laws, exempting referring institutions and participating families from liability if one child deteriorates or dies at the other family's home in parent-to-parent respite cooperatives.
- Pay for the needed infrastructure (coordinator) for parent-to-parent cooperatives.
- Provide funds for institutions or state agencies to create and maintain a database of families with children LWLTC to facilitate mutual support and networking.
- Provide funds to enable training and monitoring individuals willing to provide respite care.

The most effective respite program that will meet the needs of most families is one that offers a spectrum of respite choices, ranging from volunteers to parent-to-parent cooperatives, foster homes, home care nursing, medical daycare, hospice homes, inpatient respite and institutionalized care.

Sibling Issues

The chronic illness of a child affects the entire family.⁵⁰ Research indicates that having a sibling with a life-threatening illness during childhood contributes to an increased risk of adverse psychological outcomes, including low self-esteem, somatization, school problems, interpersonal aggression with peers and delinquency, feelings of isolation, anxiety, depression and anger.^{51,52,53,54,55} Attention to the psychological needs of the healthy siblings is therefore critical. The impact of a sibling's chronic illness can be ameliorated by:

- Providing healthy siblings with accurate, honest information. This takes time, expressive therapy skills, an understanding of the developmental capacities of the child, and the ability to provide appropriate interventions.
- Involving siblings in the care of the ill child. This is presently often interfered with in the hospital due to visitation restrictions and space limitations. Providing care at home increases sibling access as would changes in hospital policies.
- Providing social support for siblings through the use of child life therapy, social support groups, sibling-to-sibling networking, counseling and camps.⁵⁰
- Support by trained volunteers (with supervision by pediatric counselors.).

Children who have a sibling die often experience bodily and psychological symptoms. Children (and the larger society) experience the consequences of lack of intervention for the management of grief and loss for many years, including significant medical care costs for the common sequelae of somatization (transformation of the pain of loss into physical pain and distressing symptoms) of grief. Children who are grieving seek medical care 2-3 times as often as age-matched peers. One-third of the visits have no physical cause, compared to 13% of non-grieving children. "Processing" grief during childhood can avoid serious mental health issues later in life.⁵⁶ Children are at particular risk for complications since the stressor of sibling death occurs before the development of effective coping mechanisms. Professional guidance is often needed to facilitate effective adaptation to loss, including helping parents understand how children grieve, thereby averting unnecessary family tension.^{57,58} Adults who had loss experiences as children have poorer treatment outcomes than those experiencing loss as adults (persistent attribution of physical causes to psychological distress, higher incidence of personality disturbances, lower marriage rates, higher prevalence of

living alone, and increased difficulties resulting in unstable relationships⁵⁹). Thus, in order to be effective, grief interventions must be available at the time of loss, during childhood.

The most effective interventions for siblings living with or bereaved of a child with life-threatening illness have not been determined.⁵² Randomized, clinical trials with large sample sizes are needed to evaluate the effectiveness of interventions designed to improve the lives of siblings of children LWLTC and bereaved siblings.

Since the siblings are not the “patient,” according to current payment schema, the care advocated in this section is totally un-reimbursed at present.

Parental Issues

Parents experience intense, prolonged, and sometimes delayed grief reactions, particularly when their child dies traumatically.⁶⁰ Parents whose children were homicide victims experience increased prescription drug use, visits to their physician, and distress levels. Their grief can be effectively ameliorated by bereavement support groups and health promotion programs.⁶⁰

It is important to consider the morbidity of surviving families when designing programs for the care of children LWLTC. Effective support and bereavement services have been proven to have the following beneficial effects:

- Decreased medical costs due to somatization.
- Decreased unnecessary prescription usage.
- Decreased psychological distress, which can impact the entire family.
- Increased productivity of working parents, including faster return to work.

Community Issues

During the course of treatment, many children LWLTC return to school and community groups unprepared to accept the ill child back. School staff members and adult leaders lack training to address the needs of either the returning student or his or her classmates. Importantly, children’s rights to refuse unwanted care while at school are routinely abrogated. The child’s right to forgo CPR, a therapy rarely beneficial in children with non-cardiac conditions, has been recognized. However, due to fears of litigation and lack of education, schools often insist on calling the emergency medical system. Thus, the child must choose between returning to school and risking being subjected to CPR, or staying at home, away from peers, deprived of the opportunity to engage in age-appropriate activities, learning and socializing to the last.

Aside from the CPR issue, more routine problems exist in the interface of school and the child LWLTC. Chronically ill children LWLTC commonly have behavioral problems on returning to school, including poor social competency.⁶¹ They are often teased and rejected by peers as well. The current palliative care reimbursement structure does not allow payment for services to assist the child and schools or community groups with this transition. Only a few large hospice programs provide such un-reimbursed services to their communities. School personnel, returning students and classmates who received services through one of the few available hospice-provided support groups describe benefits to be:

- Ability of the ill child to focus on class work, resulting in improved grades.
- Improved class attendance for the child LWLTC.

- Increase in positive behaviors, resulting in less classroom disruption.
- Decreased somatization for patients, classmates and teachers.

Payment structures enabling provision of support services to the teacher, classmates and students are a much more compassionate, reasoned and cost-efficient response to this situation.

Education

Increased availability of knowledgeable professionals with competence in pediatric palliative care will markedly improve the quality of life of children LWLTC.^{11,62} Professional education in palliative care must become a top priority in order to realize this potential. The hospital-based critical care pediatrician who cares for dying children in an ICU needs education pertaining to the ICU which differs from the educational needs of community-based primary care pediatricians caring for terminally ill children in their homes.^{11,14} Similarly, nurses involved in pediatric home health or hospice services will need different education and skills than those serving in children's hospitals, on oncology wards, or in pediatric or neonatal ICUs.

Education in palliative care is personnel-intensive. Palliative care is philosophically, personally and emotionally challenging. Effective techniques in providing this education are both time-consuming and emotionally taxing. Appropriate faculty expertise, time and resources must be mandated to address these issues. Schools of medicine and nursing must be committed to have experienced faculty and supportive services available.^{46,63,64}

Key components of pediatric palliative care education must include:

- The value and importance of palliative care interventions for children, families and society.
- How to function within an interdisciplinary team.
- The rights of patients LWLTC and their families, as determined by the law and relevant ethical thinking.¹¹
- Communication skills, including breaking bad news and negotiating goals of care with compassion, insight and empathy.^{11,14,62,65,66}
- How to manage prognostic uncertainty.¹¹
- How to negotiate decisions regarding life-sustaining interventions, including the expected outcome of each option.¹¹
- Effective pain and symptom management.^{11,14,62,63,67}
- Management of anticipatory grief and bereavement.^{11,14,62,63,67}
- Spiritual dimensions of life-threatening conditions.^{11,14}
- Complementary and alternative medicine techniques.¹¹
- Awareness of the value of including volunteers, community organizations, schools and spiritual leaders in addressing the multifaceted needs of children and families receiving pediatric palliative care services.⁶⁴
- Awareness of local/community/regional support and education resources for families facing a childhood life-threatening condition.⁶⁴
- Provision of education for parents, community health providers, volunteers, respite workers, school and community organizations to provide reassurance and continuity of care.
- The ability to interpret palliative care research.
- Health economics of palliative care.

Measures to effect priority in pediatric palliative care education include:

- Recognition that staff education to care for the child LWLTC is urgently needed. Financial incentives for training must be made available. Tuition sponsorship, discounted liability coverage or bonuses are options to consider. Institutions that make palliative care a priority should also receive tangible assistance.
- Allocation of sufficient resources for the development and implementation of innovative curricula and training programs in schools of medicine and nursing,^{67,68} social work, and psychology, among other relevant disciplines, including the development of minimal standards for program content and competency-based testing.
- Increasing faculty time for providing palliative care education.
- Incorporating palliative care training into professional education curricula. This education would be required for certification of pediatric healthcare providers (e.g., board certification, state licensure renewal program requirements, hospital and Medicaid provider privileges).
- Requiring palliative care certification for all current practitioners who routinely encounter children LWLTC, including, and in particular, pediatric subspecialists. Training for home care and hospice workers, non-professional caregivers, parent aides, and volunteers to provide needed care, particularly in the terminal phase.
- Education within healthcare institutions that meets the needs of primary care physicians, specialty physicians and healthcare organization staff.

Benefits of investing in professional education in pediatric palliative care may be expected to include:

- Improved access to competent care that is most appropriate to children LWLTC and their families and is consistent with their values.
- Improved trust between pediatric healthcare providers and their patients/families.
- Improved family confidence in their own ability to meet their child's needs.
- Prevention of unnecessary, non-beneficial or burdensome and costly care measures (such as recurrent visits to the emergency room for pain) and unnecessary ICU intervention.

Public Policy and Ethical Concerns

Public policy should uphold the ethical practice of medicine and seek ways to advocate for children. Historically, medical care institutions have treated patients like diseases rather than persons. In the case of children, advocacy should enable children to participate meaningfully in the decision-making process, in a developmentally appropriate manner. Healthcare professionals who provide care for children have a responsibility to ascertain child/family values in deriving these goals.

Recommended Institutional Policy and Procedures to Facilitate Pediatric Palliative Care

- Competency in palliative care should be required for credentialing and continued employment in care areas where children LWLTC are encountered. This would include all members of the interdisciplinary team, with content specific to their discipline. For instance, nurses and physicians must be competent in pain and symptom management, and ethical and legal issues in medical decision-making for and with children, while social workers, chaplains and child-life therapists need to know developmental perspectives on chronic illness and death. Standards and testing for such competencies must be devised.

- Acute care hospitals must adapt their physical attributes to better support families' needs (waiting areas, sleep accommodations for parents and siblings when the child is in the terminal phase, supervised play areas and counseling for siblings, food service areas, privacy areas, a palliative care unit or room).
- Acute care hospitals must be staffed by professionals who are competent in the care of children LWLTC (a staff with broad expertise in palliative care principles as well as a palliative care consult team).
- Medication administration policies must be flexible (e.g., ability to administer medications from home, keep medications at the bedside, enable parental control, and allow compounding of medications to meet the unique needs of children).
- Unnecessary visitation restrictions should be abandoned. Current isolation techniques make these rules virtually obsolete.
- Children's and families' rights to forgo medical treatment, including artificial nutrition and hydration, should be enforced and upheld in nursing homes, hospitals, schools or other institutions and hospices, and by emergency services personnel.
- The applicability of Out-of-Hospital DNR and other advance directives to children and infants must be legislated.
- Children who are discharged from the acute care setting who will no longer benefit from and who do not desire resuscitation should automatically be given a written advance care plan, including an Out-of-Hospital DNR, and the local emergency medical services should be notified.

Research in Palliative Care

To ensure children receive high-quality, effective care, research on terminally ill children must be conducted. It is interesting that few objections to obtaining consent to conduct Phase I trials for chemotherapies in this population are raised, but frequent objections to palliative care protocols are cited. Recognizing the vulnerability of such children and families, a set of principles must guide research, regardless of the life-extending or comfort-enhancing goals of the study. If such principles are followed, institutional review boards should not hesitate to approve palliative care protocols. We suggest the following:

- Research in palliative care for children must attend to direct benefits for the child and caregiving family.
- Research design and consent procedures must be cognizant and respectful of the vulnerability of terminally ill children and their desperate families. Appropriate safeguards must be designed and enforced.
- Adequate funding for research in palliative care must be allocated to ensure that best practices and not best guesses inform the care of these children. Research should build on evidence that already exists, should be innovative, and should fill existing gaps in service.
- The benefits of current and proposed palliative care practices should be substantiated by well-designed studies.

Outcome Measures

Effective means of measuring palliative care outcomes are desperately needed. Teno, Byock and Field recently outlined the characteristics of relevant outcome measures in evaluating end-of-life care in adult patients. Even this field is in its infancy; the domains of inquiry and economic and cultural relevance are in question.⁶⁹ The questions relevant to families of children LWLTC will be different from adults and will require separate study. However, everyone agrees that physical comfort, emotional and spiritual comfort, short- and long-term family function and satisfaction as well as caregiver satisfaction and cost are important. Some tools that may be useful are included in the appendix. (See Appendix 2 for examples of measures.)

Cost Issues in Pediatric Palliative Care

Any discussion regarding pediatric palliative care must include issues of cost, cost benefits and cost savings. The exact determination of these three factors is difficult, if not impossible, due to the lack of easily accessed data, the small number of programs providing care, and different approaches of cost analysis.

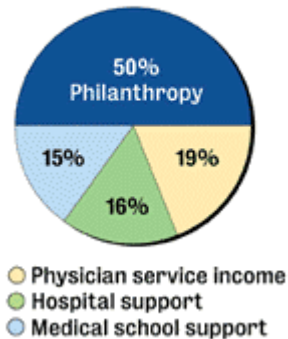
Reimbursement

The fact that pediatric palliative care and counseling regarding care goals and options is largely not reimbursed is probably the second most important barrier to the widespread acceptance and availability of palliative care services for children.^{37,70} It is a rare children's hospital that has a palliative care team or even an interdisciplinary pain team. Financial barriers only add to the difficult psychological and philosophical barriers that prevent children and their families from accessing care focusing on the child and the family as a whole and not only on the sometimes elusive goal of cure.

A year 2000 analysis of two established outpatient, hospice-based, palliative care programs providing care for children, located in different parts of the country shows 18% to 49% of the usual "medical" services billed were not reimbursed by third-party payment. Each program further provides services required by children LWLTC and their family members, such as expressive therapy (enables children to explore emotional responses when their vocabulary limits their communicative skills), pastoral/spiritual care (to explore the "whys" of illness and childhood death), anticipatory grief counseling and bereavement care, all of which is currently unpaid — attempts to bill for these valuable and necessary services will be rejected without further consideration. These services make a significant difference in the children's and families' lives; nevertheless, they are not recognized as "medically necessary" and are thus not paid services. Changes in reimbursement are needed to adequately reimburse institutions and families for the costs of palliative care, at home, when possible, and in the inpatient setting, when needed or desired.

A recent article in the American Medical News compares reimbursement patterns for palliative medical care to curative or life-prolonging care.⁷¹ The sources of funding for palliative care, according to the Lilian and Benjamin Hertzberg Care Institute at the Mount Sinai School of Medicine, is as follows:

Where the money comes from



This is clearly divergent from the funding sources for life-prolonging medical interventions.

Cost Benefits of Home Care

A pilot program delivering primarily home-based palliative care to children was in place from 1980-88 in southern California. The sole admission criterion was that the child had a catastrophic or life-threatening condition for which treatment would not arrest the process or change the outcome. Efforts to prolong life were accommodated, as desired. Families themselves and any member of the health-care team could initiate the referral. A clinical nurse specialist at the referral hospital coordinated care. She was on call 24 hours a day; community resources were utilized for home care. Over the nearly 8-year period, 300 children were referred and 226 enrolled in the home care portion of the program. Half the children had cancer and the rest had a wide variety of neurologic, gastrointestinal and newborn disorders, among other diagnoses. Median time in the program was 78.4 days, with a range of 1-549 days. Patients who accepted home care had an average length of stay of 91 days (median 48 days). These children spent 80-90% of their time at home rather than in the hospital. Children receiving home care services primarily used intermittent nursing care. Neonates and patients with severe neurologic conditions used continuous nursing services disproportionately. Social work services were used in 42.4% of cases; other services were used in fewer than 10% of cases. Costs for the entire stay averaged approximately \$3,000 (1988 dollars). The range of intermittent nursing care costs were \$0-4,950, social work costs were \$0-2,530, and extended care costs ranged from \$0-95,536.

An ongoing pediatric palliative care demonstration project in Washington State, conducted in the private pay sector and funded by the Robert Wood Johnson Foundation, has already demonstrated cost efficiencies for palliative care for children in its preliminary data analysis. Three case examples illustrate the outcomes that will occur with widespread changes in the approach to children LWLTC.

- A 16-year-old with metastatic cancer had been hospitalized for anorexia and dehydration while undergoing chemotherapy. With the new program, he remained comfortably at home instead. Pre-intervention costs: three days, \$2,660; post-intervention: four weeks, \$2,000.
- An 11-month-old with severe brain damage had frequent respiratory deterioration resulting in hospitalizations. Average monthly medical expenditures prior to the new program were \$15,115, with numerous hospitalizations. After the new program, costs remained stable (\$15,081/month), but the child remained at home and the family received 12 hours of help per day.

- A teen with metastatic cancer was hospitalized for difficult-to-control symptoms. However, her goal was to be at home. The new program enabled her to be comfortable at home by providing medical supervision, equipment and medication. Costs decreased from \$6,820 per month to \$1,690 per month.

Children with special healthcare needs consume 691 bed days per thousand children, compared to 122 bed days per thousand children without special healthcare needs.³ It is our contention that, with more effective palliative care, costs will either remain constant or decrease, the number of bed days will be reduced, and, most importantly, patient and family outcomes will improve.¹² The 1.9% of children with NACHRI chronic illness severity levels 3 and 4 in the Washington State Medicaid Study¹² accounted for 23% of total Medicaid expenditures.¹³ Average per annum expenditure for non-institutionalized children 0-17 years of age with illness severity level 4, was \$48,000/child; patients with severity level 3 averaged \$19,000/child. Health care provider and family costs for care in the hospital can be up to nine times greater than the same care provided in the home.⁷⁰ Non-healthcare costs to the family (such as travel, food, etc.) are also lower in home care, \$1,099/year as compared to \$13,975 when the child is receiving hospital care.⁷⁰ However, other costs, such as loss of income, are more common when children remain at home. These issues need to be considered when designing programs of care.

Cost Differences

Where do the higher costs of hospitalization come from? Why are they so much more?

Direct costs of home care constitute approximately 60% of total care costs and include personnel salaries and expenses, operations, and non-salary expenses (i.e., travel, office support, etc.). Costs within the hospital are often subject to “upcharges” associated with the common practice of cost shifting. In Buffalo, NY, total parenteral nutrition (intravenous “feedings”) costs \$125-\$200 per day when administered at home and \$800-\$1,200 per day in the hospital.

The average cost per child per year, cared for primarily at home, receiving comprehensive palliative and life-prolonging services for the child and family in two established pediatric palliative care programs, is \$16,177, significantly less than the \$19,000-\$48,000/child/year experience of the Washington State Medicaid agency. Moreover, this amount of money would pay for only 4-5 ICU days in a major children’s medical center. Patient cost studies for each of these established pediatric palliative home care programs demonstrate that quality care can be provided to children with serious illness at home and save thousands of dollars in clinic visits and hospital stays.

Comprehensive Pediatric Palliative Care in Action: Actual Patient Cost Studies

Patient 1, Essential Care Program, Buffalo, NY: Derrick is a 10-year-old boy, diagnosed at age 4 with brain cancer. He lives with both parents and an 11-year-old brother. He has undergone chemotherapy, radiation, and surgical procedures, but unfortunately, his cancer has recurred. He has residual headaches, deafness, and hair loss from his disease and his treatments. His kidneys and liver were damaged by previous therapies; further conventional therapies are no longer an option. As a last hope, he, his parents and doctors have chosen to attempt three consecutive stem cell transplants. Because of clear, compassionate and technically accurate conversations that have taken place with the oncologist, child life therapist and social worker, Derrick understands the stem cell transplant will only delay the spread of his cancer. However, he feels it is worth the burden of therapy. After all, he participated in gym class for the first time ever this month. His life goal is to learn to ride a bicycle, like other boys his age.

The palliative care service, working closely with the oncology service, has given Derrick and his family hope and quality time. He has been receiving palliative care services for 472 days (14 months), while receiving life-extending therapies provided by the oncology team. Home care services keep Derrick and his brother in school, his parents at work, and the family living in their own home. Conversations with the oncologist have enabled them to feel comfortable and confident in their choices; however, other children may have had different outcomes if their oncologist were unwilling to engage in these lengthy, underpaid conversations, so necessary to receive appropriate care. Over 14 months, the palliative care service has provided:

- 105 nursing visits to assess and treat symptoms, detect and treat intercurrent illnesses or complications, minimize the number of clinic visits, and to serve as a liaison with the oncology staff;
- 53 social work visits to assist his parents to cope financially, practically and socially with Derrick's situation;
- 45 child life visits to help Derrick and his brother express their fears and anxieties and to learn how to enjoy life despite limitations as well as serve as a liaison to the school and community groups to which Derrick belongs.

Total: 203 visits

Hours of service: 183 hours, not including physician counseling

Total Cost of Home Care (in addition to hospitalization care): **\$ 24,859, or \$55/day**

Costs paid by insurer: **\$16,930**, an operating loss for the hospice of \$7,929

Estimated costs in the absence of home care services, not accounting for the long-term, costly repercussions for the survivors who are separated unnecessarily from the ill child, are:

Estimated number of hospital days saved: 30 (\$1,800/day)= \$54,000

Estimated number of outpatient clinic days saved: 75 (\$150 clinic visit)=\$11,250

Total estimated cost avoidance: \$62,250

Net savings to insurer if home care services were reimbursed for costs expended: \$37,931

Decreased indirect costs to the family resulting from hospital or clinic days (gas, parking, mileage, meals away from home, loss of time from work, and childcare for sibling) are also benefits of a home-based palliative care program. Even sophisticated medical treatment can be delivered at home, often making the child and family more comfortable, while representing a substantial cost savings.

Patient 2, Kaleidoscope Kids, Salt Lake City, UT: Terry was a 16-year-old diagnosed with a rare form of leukemia. She was admitted to the palliative care program at the time of her diagnosis and was on service for 22 months until her death. During the last 12 months of her life, she underwent a bone marrow transplant. Unfortunately, she developed severe fungal infections and had a prolonged stay in the ICU. The total costs of hospitalization and clinic visits over the 22 months from her diagnosis to death amounted to \$595,000 or \$901/day. Her home care costs for the same period, including nearly \$180,000 in pharmacy charges, were \$207,903 or \$315/day. She received the same expensive intravenous anti-fungal therapy, antibiotics, total parenteral nutrition and blood products at home that she did in the ICU. The cost savings of home care alone do not tell the

whole story, however. Terry herself said it best: “It is so nice to be at home with my family. Friends can come over and it’s just best to be home with your own things.” Her family, friends and high school classmates visited freely; she was chosen to be the prom queen. Just 3 months before her death, she reigned as queen at the prom from her wheelchair.

Patient 3, Essential Care Program, Buffalo, NY: Jimmy, an 8-year-old, had a neurodegenerative disease, adrenoleukodystrophy (ALD). He underwent a bone marrow transplant in an attempt for a cure. The cost was \$100,000. Other important costs were prolonged isolation, a potentially accelerated death, and extensive lost time from work for his parents. Unfortunately, the transplant was not successful for Jimmy, though it works for 65% of children with this diagnosis in the most experienced institutions. Jimmy’s condition rapidly deteriorated and he became totally dependent, requiring full care, a common endpoint of his underlying disorder. He was fed liquid nutrition through a tube in his stomach. He lost the use of all his muscles, requiring turning every 2 hours, day and night, to prevent bedsores. He had numerous seizures and frequent episodes of pneumonia. He did not attend school and did not speak. His care demands placed him at risk to be institutionalized. However, Jimmy, despite all his problems, appeared to know that he was with his family and seemed to appreciate being with them. He was able to enjoy some activities. He was enrolled in a New York State Medicaid Waiver program that provided 16 hours of paid nursing care a day, allowing him to remain at home and participate in some family activities. Shortly before his death, his nurse prepared him to go on a sledding outing with his family.

In his last 24 months, Jimmy was admitted to the hospital 10 times (5.2 hospital days average length of stay, primarily in the Pediatric Intensive Care Unit, estimated average \$2,000/day). We estimate the program prevented two other admissions, a potential cost savings of \$20,000.

Total home care costs over 24 months (in addition to hospitalized care):

Nurses (Licensed Practical Nurse):	16 hrs./day	(\$20/hr.)	\$226,800
Rehab (Physical and Occupational Therapy):	222 visits	(\$45/visit)	\$ 9,900
Skilled nursing:	100 visits	(\$39/visit)	\$ 3,900
Social work:	42 visits	(\$33.33/visit)	\$ 1,400
Child life:	18 visits	(\$24/visit)	\$ 432
Capital equipment purchase (lift and wheelchair):			\$ 10,000
Total cost of home care (2 yrs. — 50 days):		(\$371/day)	\$252,432

This child represents an argument for restructuring not only home care costs, but also mechanisms for home care delivery. Nursing assessments are an important part of care, particularly as the final days of life unfold and the child’s condition is changing rapidly. But minute-to-minute management of stable patients by a nurse is rarely necessary. If we as a society feel that parents with no medical background can be trained to care for their own children at home, why do we require either a Licensed Practical Nurse, Licensed Vocational Nurse or Registered Nurse to care for the child in the parents’ absence? It would be much more cost-efficient to train lay providers, including parent-to-parent respite care, medical daycare, or trained sitters to be available to assist in the care of these children and provide needed time for the family to maintain itself and succeed in its other endeavors. The expenditures for this child’s care are extremely high, and this is primarily related to the semi-skilled nursing hours provided.

Patient 4, Galveston, TX: Faisal was a 14-year-old boy sent from his home in a third world country to live in the United States with his brother, to improve his chance of a successful life.

Unfortunately, Faisal was found at the bottom of the pool. Aggressive resuscitation was ineffective in preserving his brain function. The palliative care team, consisting of a physician, nurse, social worker, chaplain and child life therapist was consulted. Painful discussions of Faisal's poor prognosis were conducted in the ICU, as well as negotiation of the next steps. Options discussed included transfer to a large room to accommodate the brother's large support system and traditions. In the meantime, the social worker tried desperately to obtain a visa for Faisal's parents to be with him one last time. The boy was transferred the next morning to the larger, private room. The interdisciplinary team awaited him and his family. The brother and 30 members of his congregation surrounded Faisal's bed in a circle. Explanations of his prognosis, decisions that had been made, and the plan of care were shared at the brother's request. Questions were answered and affirmation obtained. The group chanted for an hour. They then wept, pulling at the child's sheets while the team listened to their concerns and pain. The physician and nurse monitored the boy's comfort. The child life therapist drew the children aside to listen to their impressions. The chaplain conferred with his counterpart, helping to explain. Photographs were taken. Then the "family" stated they were ready for extubation (removal of the life-support machines). The physician removed the breathing tube while the "family" chanted, remaining close to monitor and respond to any apparent discomfort.

This care would have been reimbursed at over \$2000 if it occurred in the cramped ICU, surrounded by fearful families, with machinery whirring and beeping. Since it occurred in a private space that met the unique needs of this child and family under the hospice benefit, the total remuneration for services rendered was \$440. Of that, \$400 went to the hospital, by contractual arrangement, leaving \$40 to divide among the personnel hours of the physician, nurse, chaplain, social worker and child life specialist, each of whom spent from 2 to 8 hours caring for the child that day alone.

Recommendations based on these case scenarios

Reimbursement schema must recognize the benefits of palliative care in the home as well as in other settings, including acute care hospitals. Interventions needed to realize the potential benefits of palliative care include extensive physician counseling, home nursing, psychosocial, spiritual and allied health therapies, ICU-based palliative care and respite care/sitters. These services, as well as provision of the medications, intravenous therapies and equipment needed to maintain the child and family, are all "medically necessary."

Recommendations for future research

Research should be done to develop accurate assessments of quality of life for these children and their families at the same time that a detailed cost analysis of home vs. institutional care is performed. We need to understand what benefit we achieve relative to the costs. Most importantly, do these children and their families have an improved quality of life? Do they have fewer acute care and ICU admissions or decreased lengths of stay? Does having control over day-to-day care and decisions improve the child's and families' experiences? Can more children die in the place of their choice if psychosocial support is offered earlier in the disease process? Do more children have advance directives with effective physician counseling and support early in the process? How are parents affected by being transformed into medical care providers? How are siblings affected by the application of palliative care early in the course of illness? What is the long-term outcome for siblings when different types and locations of care are employed and different goals of care are used as guides? What does it cost to give effective, family-centered care to these children? What form should reimbursement take? Fragmentation of care is problematic for families. Does a case coordinator, effective in many similar situations, ameliorate these problems? These questions can

only be answered in large-scale studies; thus, we recommend additional federal funding for institutional, county-wide, statewide or regional demonstration projects, to determine the most effective and efficient models of care. The current children's hospice demonstration project (Program of All-inclusive Care for Children - PACC) is only one model; a variety of solutions should be attempted in order to accommodate local needs and cultural norms surrounding medical care, as well as community resources and individual family and patient preferences.

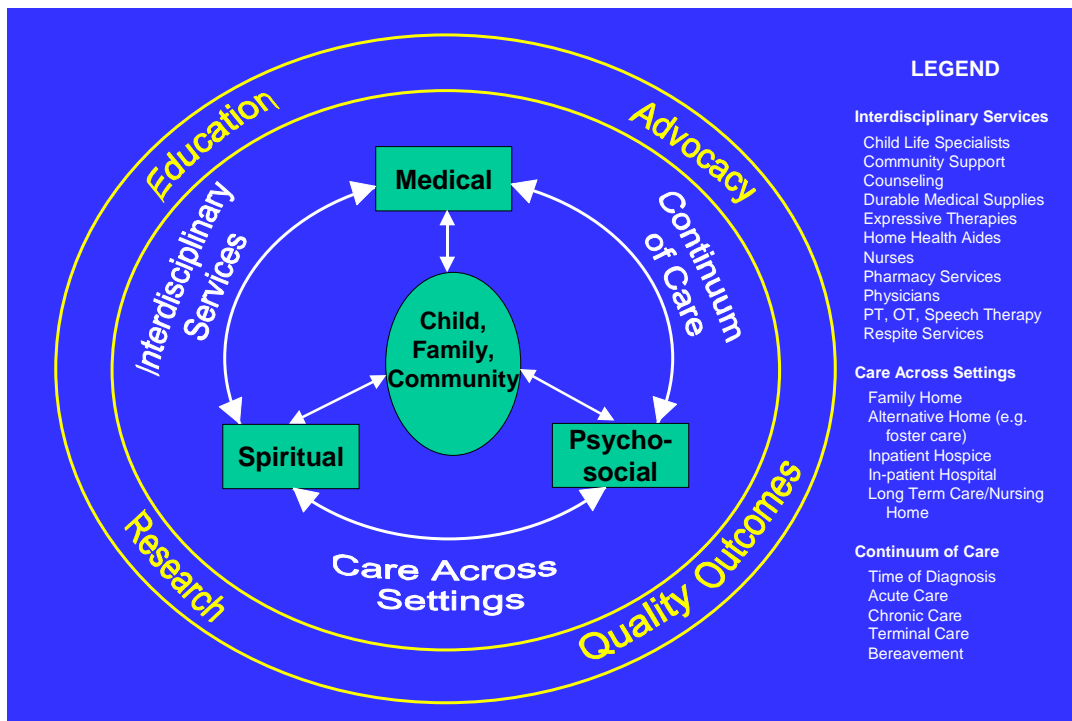
Financial and Policy Issues

Family financial ruin must also be addressed. Exclusion from the ability to change employment due to insurance issues is a critical problem. Families who forgo a full-time paid job in order to care for their child should be offered a substantial tax credit or possibly payment for the care provided.

Finally, palliative care reimbursement should allow for the costs of training families, school personnel, volunteers, and others who care for these children. Less highly educated personnel may be able to care for these children, given adequate training. For children who cannot be maintained at home, fair financing of reasonable alternative care venues must be available. We additionally feel that children who can benefit from going to school should be encouraged to do so, and facilitation should be provided that will allow that to occur. However, we feel equally strongly that children who are unable to interact meaningfully with others and whose learning plan involves self-care only, should not be cared for in the school setting. This is an inefficient and unfair allocation of resources, a poor substitute for counseling and respite care, and is financially devastating for school systems struggling to benefit the majority of children in the community.

Proposed Clinical Model of Pediatric Palliative Care Programs

An ideal pediatric palliative care program will address the needs of the child, family and larger community. Care will be delivered in the home, hospice, hospital or ICU. Program elements can be tailored to meet the current needs of the child and family, with elements being added or deleted as the child's condition changes. Implementation of the program should not be dependent on forgoing other elements of care that are of value, nor contingent upon a certain prognosis of the time of death. There is no single care delivery model that will work in every community. The delivery model should take into account existing resources and programs, and not duplicate such services, but rather build upon them.



Appendix 1

Universal Principles of Pediatric Palliative Care⁷² A set of universal principles of pediatric palliative care, adapted from national and international professional societies^{6,73,74,75,76,77,78,79,80,81,82,83,84,85} has been crafted by leading experts in the field. Implementation of these principles will guide program developers to effective solutions.

1. The sole admission criterion for palliative care programs is that the child is not predicted to survive to adulthood. Prognosis for short-term survival should not be required, as it interferes with the provision of critical support from the time of diagnosis.
2. The unit of care is the child and the family. Family is defined as the persons who provide physical, psychological, spiritual and social comfort to the child, regardless of genetic relationship.
3. Palliative/hospice services should be accessible to children and their families in a setting that is desired and/or appropriate for their needs. It may be inpatient hospice, hospital intensive care unit, the home or other settings. Research indicates that the home is generally considered the preferred site of living until death. Home care results in enhanced bereavement outcomes for family members who otherwise may have limited access to the child. However, a substantial minority of children and their families prefer the child to die in familiar institutional settings, surrounded by their usual caregivers.
4. Palliative care is not directed at foreshortening life. Symptom management is accomplished through means acceptable to the patient and the family.
5. Palliative care focuses on the relief of physical, social, psychological and existential or spiritual pain for the child and the family, whether or not they have chosen to continue with life-prolonging therapies.
6. Children LWLTC and their families should have access to a team of caregivers, or at minimum, a “keyworker” or care coordinator whose care is seamless (i.e., cares for them where they prefer to be, regardless of the goals of care).¹
7. Care is designed to enhance the quality of life for the child and family; the child and family are included in designing the priorities of care, using comprehensive information regarding the disease and treatment options.
8. The care team recognizes the individuality of each child and his or her family, and upholds their values, wishes and beliefs unless significant harm is at hand.
9. Pediatric palliative care is optimally delivered by an interdisciplinary team with pediatric knowledge, and generally includes trained volunteers, social workers, nurses, physicians, spiritual counselors and psychologists. Involvement from the time of diagnosis demands a respectful, truly integrated approach with the team of experts who are attempting to effect cure and/or life-prolongation.⁸⁶
10. The palliative care team must be available to the family 24 hours a day, 365 days a year.

11. The provision of respite, whether for a few hours or a few days at a time, is an essential service for families whose child has a chronic, life-threatening condition.
12. Families should be able to refer themselves to receive hospice/palliative care services.
13. Interdisciplinary palliative/hospice services should be recognized as legitimate and valuable medical services and should be reimbursed adequately, to enable viability and availability of these services.
14. Supportive and bereavement care should be available as long as necessary to all those who are affected by the child's death by a professional team educated and trained in palliative care.
15. Providing pediatric palliative care is difficult, rewarding work. Direct caregivers must be provided both formal and informal psychosocial support and supervision.

Appendix 2: Proposed Outcome Measures for Pediatric Palliative Care

1. McMaster Family Assessment Device to assess global family functioning (53-item self-report measure)
 - Byles J, Byrne C, Boyle MH, Oxford OR. Ontario Child Health Study: Reliability and Validity of the General Functioning Subscale of the McMaster Family Assessment Device. *Fam Process*. 1988; 27: 97-104.
 - Miller IW, Bishop DS, Epstein NV, Keitner GI. The McMaster Family Assessment Device: reliability and validity. *J Marital Fam Therapy*. 1985; 11: 345-356.
 - Stevenson-Hinde J, Akister J. The McMaster model of family functioning: observer and parental ratings in a non-clinical sample. *Fam Process*. 1995; 34: 337-347.
2. Brief Symptom Inventory to measure parent psychological adjustment (53-item self-report)
 - Derogatis L, Melisaratos N. The Brief Symptom Inventory: an introductory report. *Psychol Med*. 1983; 13: 595-605.
3. Dyadic Adjustment Scale to measure marital function (32-item Likert scale)
 - Spanier GB. *Dyadic Adjustment Scale: Manual*. North Tonawanda, NY: Multi-Health Systems; 1989.
4. Multidimensional Assessment of Parental Satisfaction (MAPS) for Children with Special Health Care Needs, 12-item measure with excellent reliability, validity and psychometric integrity
 - Ireys HT, Perry JJ. Development and evaluation of a satisfaction scale for parents of children with special health care needs. *Pediatrics*. 1999; 104: 1182-91.
5. Non-Medical Costs Phone Interview
 - In: Birenbaum & Clarke-Steffen. Terminal care costs in childhood cancer. *Pediatric Nursing*. 1992; 18: 285-8.
6. Pediatric Oncology Quality of Life Scale
 - Bradlyn AS, et al. Quality of life research in pediatric oncology: Research methods and barriers. *Cancer*. 1996; 78: 1333-9.
7. Bradlyn AS, et al. An investigation of the validity of the Quality of Well-Being Scale with pediatric oncology patients. *Health Psychol*. 1993; 12: 246-50.
8. Modified Lansky Play Performance Scale
 - Lansky SB, List MA, et al. The measurement of performance in childhood cancer patients. *Cancer*. 1987; 60: 1651-56.
9. Peds QL. This is a modular instrument that can be adapted to different disease states.
 - Varni JW, Seid M, Rode CA. The Peds QL: Measurement model for the pediatric quality of life inventory. *Med Care*. 1999; 37(2): 126-139.
10. Various bereavement assessment tools. Discussed in Stokes, et al. The challenge of evaluating a child bereavement program. *Palliat Med*. 1997; 11: 179-190.

Suggested Additional Reading Material

Frager G. Palliative care and terminal care of children. *Child Adolesc Psychiatr Clin N Am.* 1997; 6(4): 889-909.

Goldman A (Ed). Care of the dying child. New York: Oxford University Press, 1998.

Maltoni M, Travaglini C, Santi M, Nanni O, et al. Evaluation of the cost of home care for terminally ill cancer patients. *Support Care Cancer.* 1997; 5(5): 396-401.

McGrath PA, Goldman A, Stevens MM, Davis B, Howell D, Eng B, Dominica F, Pollard B, Faulkner K W, Levetown M, Carter MA. Chapter 19, Paediatric palliative care. In Doyle D, Hanks GWC, MacDonald N (Eds). Oxford Textbook of Palliative Medicine (pp. 1013-1119). New York: Oxford University Press, 1998.

Wolfe J, Grier HE, Klar N, Levin SB, Ellenbogen JM. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med.* 2000; 342: 326-33.

Endnotes

- ¹ Newacheck PW, Strickland B, Shonkoff JP, et al. An epidemiologic profile of children with special health care needs. *Pediatrics*. 1998; 102: 117-123.
- ² Gay JG, Muldoon JH, Neff JM, Wing LJ. Profiling the health services needs of populations: Description and uses of the NACHRI classification of congenital and chronic health conditions. *Pediatr Ann*. 1997; 26: 655-66.
- ³ Newacheck PA, Hatton N. Prevalence and impact of disabling conditions of childhood. *Am J Public Health*. 1998; 88: 610-617.
- ⁴ Feudtner C, Christakis D, Connell FA. Pediatric deaths attributable to complex chronic conditions: A population-based study of Washington State, 1980-1997. *Pediatrics*. 2000; 106: 205-209.
- ⁵ Guyer B, Hoyert DL, Martin JA, et al. Annual summary of vital statistics — 1998. *Pediatrics*. 1999; 104(6): 1229-1246.
- ⁶ Association for Children with Life-threatening or Terminal Conditions and their Families, Royal College of Pediatrics and Child Health. *A guide to the development of children's palliative care services*. 1997. To obtain: Association for Children with Life-Threatening or Terminal Conditions & Their Families, 65 St. Michael's Hill, Bristol BS2 8DZ, England, Tel: 0117-922-1556, Fax: 0117-930-4707. Royal College of Paediatrics and Child Health, 5 St. Andrews Place, Regent's Park, London NW1 4LB, England, Tel: 0171-486-6151, Fax: 0171-486-6009.
- ⁷ Hilary Maguire, An Assessment of the Needs of Children with a Life-limiting or Terminal Illness and Their Families, The Northern Ireland Children's Hospice Project, 2000.
- ⁸ Field MJ and Cassel CK. Approaching Death, Improving Care Near the End of Life. National Academy Press, Washington, D.C. 1997.
- ⁹ Faulkner KW, Armstrong-Dailey A. Care of the dying child. In: Pizzo P, Poplack D (eds) Principles and Practice of Pediatric Oncology 3rd edition. Philadelphia: Lippincott-Raven Publishers, 1997; 1349-1351.
- ¹⁰ Koocher GP, Gudas LJ. Terminal and life threatening illness in childhood. In: Levine MD, Carey WB, Crocker AC, Gross RT (eds). Developmental-behavioral Pediatrics. Philadelphia: WB Saunders, 1992; 327-336.
- ¹¹ American Academy of Pediatrics Committee on Bioethics and Hospital Care. Palliative care for children. *Pediatrics*. 2000; 106(2): 351-357.
- ¹² Newacheck PW, Strickland B, Shonkoff JP, et al. An epidemiologic profile of children with special health care needs. *Pediatrics*. 1998; 102:117-123.
- ¹³ Gay JG, Muldoon JH, Neff JM, Wing LJ. Profiling the health services needs of populations: Description and uses of the NACHRI classification of congenital and chronic health conditions. *Pediatr Ann*. 1997; 26: 655-663.
- ¹⁴ Report of a Joint Working Party of the Association for Children with Life-Threatening or Terminal Conditions and their Families and the Royal College of Paediatrics and Child Health. *A Guide to the Development of Children's Palliative Care Services*, 1997, Bristol.
- ¹⁵ Evans D. Kaleidoscope Kids Program, Community Nursing Service, Salt Lake City, Utah.
- ¹⁶ National Cancer Institute's Surveillance Epidemiology and End Results (SEER) Program. *CA: A Cancer Journal for Clinicians*. 2001; 51: 15-36.
- ¹⁷ Bowen KA, Marshall WN. Pediatric death certification. *Arch Pediatr Adolesc Med*. 1998; 152: 852-854.
- ¹⁸ McCallum DE, Byrne P, Bruera E. How children die in hospital. *J Pain Symptom Manage*. 2000; 20(6): 417-423.
- ¹⁹ US Mortality Public Use Data Tape, 1998, National Center for Health Statistics, Centers for Disease Control and Prevention, 2000.

- ²⁰ Oleske JM, Czarniecki L. Continuum of palliative care: Lessons from caring for children infected with HIV-1. *Lancet*. 1999; 354: 1287-1290.
- ²¹ Armstrong-Dailey A, Fair C. Respite and terminal care for children with HIV infection and their families. In: Pizzo PA, Wilfert CM (eds). Pediatric AIDS: The Challenge of HIV Infection in Infancy, Childhood and Adolescence. Baltimore, MD: Williams & Wilkins; 1994: 829-838.
- ²² Lenker SL, Lubeck DP, Vosler A. Planning community-wide services for persons with HIV infection in an area of moderate incidence. *Public Health Rep* – Hyattsville. 1993 May-June; 108(3): 3850-3893.
- ²³ Attig T. Beyond Pain: The existential suffering of children. *J Palliat Care*. 1996; 12: 20-23.
- ²⁴ Lewis SY, Haiken HJ, Hoyt LG. Living beyond the odds: A psychosocial perspective of long-term survivors of pediatric human immunodeficiency virus infection. *J Dev Behav Pediatr*. 1994; 15: S12-17.
- ²⁵ Liben S. Pediatric palliative medicine: Obstacles to overcome. *J Palliat Care*. 1996; 12: 24-28.
- ²⁶ Fleischman AR, Nolan K, Dubler NN, et al. Caring for gravely ill infants and children. *Pediatrics*. 1994; 94: 433-439.
- ²⁷ Robinson WM, Ravilly S, Berde C, et al. End-of-life care in cystic fibrosis. *Pediatrics*. 1996; 100: 205-209.
- ²⁸ Walco GA, Cassidy RC, Schechter NL. The ethics of pain control in infants and children. *N Engl J Med*. 1994; 331: 541-544.
- ²⁹ Martinson IM. Hospice care for children: Past, present and future. *J Pediatr Oncol Nurs*. 1993; 10: 93-98.
- ³⁰ American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health. The pediatrician and childhood bereavement. *Pediatrics*. 2000; 105: 445-447.
- ³¹ Davies B, Clarke D, Connaughty S, et al. Caring for dying children: Nurses' experiences. *Pediatr Nurs*. 1996; 22(6): 500-507.
- ³² Goldman A. Home care of the dying child. *J Palliat Care*. 1996; 12: 16-19.
- ³³ Lauer M, Camitta B. Home care for dying children: A nursing model. *J Pediatr*. 1980; 97: 1032-1035.
- ³⁴ Martinson IM, Moldow DG, Armstrong GO, et al. Home care for children dying of cancer. *Res Nurs Health*. 1986; 9: 11-16.
- ³⁵ Martinson IM. Pediatric hospice nursing. *Ann Rev Nurs Res*. 1995; 13: 195-214.
- ³⁶ Boland M, Burr C, Harvey D. Pediatric AIDS revisited: Family, social and legal issues. *Semin Pediatr Infect Dis*. 1995; 6: 40-45.
- ³⁷ Schweitzer SO, Mitchell B, Landsverk J, Laparan L. The costs of a pediatric hospice program. *Public Health Rep*. 1993; 108(1): 37-44.
- ³⁸ Vickers JL, Carlisle C. Choices and control: Parental experiences in pediatric terminal home care. *J Pediatr Oncol Nurs*. 2000; 17(1): 12-21.
- ³⁹ Levetown. Unpublished survey of National Hospice Organization member hospices, 1994.
- ⁴⁰ Hilden JM, Fairclough DL, Link MP, Foley KM, Clarridge BC, Schnipper LE, Mayer RJ. Attitudes and practices among pediatric oncologists regarding end-of-life care: Results of the 1998 American Society of Clinical Oncology Survey. *J Clin Oncol*. 2001; 19: 205-212.
- ⁴¹ Pierce SF. Improving end-of-life care: Gathering suggestions from family members. *Nursing Forum*. 1999; 34(2): 5-14.
- ⁴² Meert K, Thurston C, Sarnaik A. Parental experience with death in the pediatric ICU. *Crit Care Med*. 1999; 27(12): A83. (Suppl).
- ⁴³ Randle H. What happens now? Information for parents whose child has died in A&E. *Paediatric Nursing*. 1998; 0(4): 20-21.

- ⁴⁴ Woolley H, Stein A, Forrest GC, Baum JD. Imparting the diagnosis of life-threatening illness in children. *BMJ*. 1989; 298: 1623-1626.
- ⁴⁵ Goldman A, Christie D. Children with cancer talk about their own death with their families. *Pediatr Hematol Oncol*. 1993; 10: 223-231.
- ⁴⁶ Charlton R. Medical education – addressing the needs of the dying child. *Palliat Med*. 1996; 10: 240-246.
- ⁴⁷ Wolfe J, Grier HE, Klar N, Levin SB, Ellenbogen JM. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med*. 2000; 342: 326-
- ⁴⁸ West Michigan Health Systems Agency. Staff paper: An overview of respite care programs. 1979.
- ⁴⁹ Kirk S. Families' experiences of caring at home for a technology-dependent child: A review of the literature. *Child Care Health Dev*. 1998; 24(2): 101-114.
- ⁵⁰ Harbeck-Weber C, McKee DH. Prevention of emotional and behavioral distress in children experiencing hospitalization and chronic illness. Chapter 9. In: Roberts MC (ed). Handbook of Pediatric Psychology, Second Edition. New York: The Guilford Press. 1995; 167-184.
- ⁵¹ Sahler OJ, Roghman KJ, Carpenter PJ, et al. Sibling adaptation to childhood cancer collaborative study: Prevalence of sibling distress and definition of adaptational levels. *J Dev Behav Pediatr*. 1994; 15(5): 353-366.
- ⁵² Williams PD. Siblings and pediatric chronic illness: A review of the literature. *Int J Nurs Stud*. 1997; 34(4): 312-323.
- ⁵³ Vance JC, Fazan LE, Satterwhite B, Pless IB. Effects of nephrotic syndrome on the family: A controlled study. *Pediatrics*. 1980; 65: 948-955.
- ⁵⁴ Breslau N, Prabucki K. Siblings of disabled children: Effects of chronic stress in the family. *Arch Gen Psychiatry*. 1987; 44: 1040-1046.
- ⁵⁵ Williams PD, Lorenzo FM, Borja M. Pediatric chronic illness: Effects of siblings and mothers. *Matern Child Nurs J*. 1993; 21: 111-121.
- ⁵⁶ Van Epps J, Opie ND, Goodwin T. Themes in the bereavement experience of inner-city adolescents. *J Child Adolesc Psychiatric Nurs*. 1997; 10(1): 25-36.
- ⁵⁷ DeMaso DR, Meyer EC, Beasley PJ. What do I say to my surviving children? *J Am Acad Child Adolesc Psychiatry*. 1997; 6(9): 1299-1302.
- ⁵⁸ Gillance H, Tucker A, Aldridge J, Wright JB. Bereavement: providing support for siblings. *Paediatr Nurs*. 1997; 9(5): 22-24.
- ⁵⁹ Mallouh SK, Abbey SE, Gillies LA. The role of loss in treatment outcomes of persistent somatization. *General Hospital Psychiatry*. 1995; 17(1): 187-191.
- ⁶⁰ Murphy SA. A bereavement intervention for parents following the sudden, violent deaths of their 12- to 28-year-old children: Description and applications to clinical practice. *Can J Nurs Res*. 1997; 29(4): 51-72.
- ⁶¹ Olson AL, Boyle WE, Evans MW, Zug LA. Overall function in rural childhood cancer survivors. The role of social competence and emotional health. *Clin Pediatr*. 1995; 32(6): 334-342.
- ⁶² Sahler OJZ, Frager G, Levetown M, et al. Medical education about end-of-life care in the pediatric setting: Principles, challenges and opportunities. *Pediatrics*. 2000; 105(3): 575-584.
- ⁶³ Khaneja S, Milrod B. Educational needs among pediatricians regarding caring for terminally ill children (see comments). Comment in: *Arch Pediatr Adolesc Med*. 1998; Sep; 152(9): 837-838. *Arch of Pediatr Adolesc Med*. 1998; 152(9): 909-914.
- ⁶⁴ McGlaufflin, H. Training volunteers and professionals to work with grieving children and their families. *Am J Hospice Palliat Care*. 1996 (March/April): 22-26.
- ⁶⁵ Levetown M. Palliative care in the intensive care unit. *New Horizons*. 1998; 6: 383-397.
- ⁶⁶ Shields CE. Giving patients bad news. *Prim Care*. 1998; 25(2): 381-390.

- ⁶⁷ Farrell MJ. National palliative care education and training needs analysis. *Contemp Nurs*. 1998; 7: 60-67.
- ⁶⁸ MacDonald N. Palliative care education: a global imperative. In: von Gunten CF (ed). Palliative Care and Rehabilitation of Cancer Patients. Boston: Kluwer Academic Publishers; 1999.
- ⁶⁹ Teno JM, Byock I, Field MJ. Research agenda for developing measures to examine quality of care and quality of life of patients diagnosed with life-limiting illness. *J Pain Symptom Manage*. 1999; 17: 75-82.
- ⁷⁰ Birenbaum LK, Clarke-Steffen L. Terminal care costs in childhood cancer. *Pediatric Nursing*. 1992; 18(3): 285-288.
- ⁷¹ Foubister V. Professional Issues: Palliative care: Mainstream model, American Medical News, Feb 26, 2001.
- ⁷² National Hospice and Palliative Care Organization. Compendium of Pediatric Palliative Care. Alexandria, VA: National Hospice and Palliative Care Organization, 2000.
- ⁷³ United States General Accounting Office, Report to the Chairman, Committee on Finance, U.S. Senate. Home care experiences of families with chronically ill children. Gaithersburg, MD: GAO/HRD-89-73, 1989.
- ⁷⁴ Corr CA, Corr DM. Pediatric hospice care. *Pediatrics*. 1985; 76(5): 774-780.
- ⁷⁵ Frager G. Pediatric palliative care: Building the model, bridging the gaps. *J Pall Care*. 1996; 1 2(3): 9-12.
- ⁷⁶ World Health Organization. Cancer pain relief and palliative care in children. Geneva, Switzerland, 1998.
- ⁷⁷ Association for Children with Life-Threatening or Terminal Conditions and Their Families. ACTPACK. 1996. To obtain: Association for Children with Life-Threatening or Terminal Conditions & Their Families, 65 St. Michael's Hill, Bristol BS2 8DZ, England, Tel: 0117-922-1556, Fax: 0117-930-4707.
- ⁷⁸ Children's Hospice International. Definition of children's hospice care. Alexandria, VA, 1989. To obtain: 2202 Mt. Vernon Avenue, Suite 3C, Alexandria, VA 22301, Tel: 703-684-0330, www.chionline.org.
- ⁷⁹ Sumner L. EOL Care for Infants and Children. In: Ferrell, B. Quality of Life, A Nursing Challenge. Meniscus Publ, *in press*.
- ⁸⁰ Lauer ME, Mulhern RK, Bohne JB, Camitta BM. Children's perceptions of their sibling's death at home or hospital: The precursors of differential adjustment. *Cancer Nursing*. 1985; 8(1): 21-7.
- ⁸¹ Byrne CS. Speaking up for the little ones. *Hospice*. 1996; 7(5): 26-29.
- ⁸² International Work Group on Death, Dying and Bereavement. Statements on Death, Dying and Bereavement. Available from IWG Secretariat, c/o Dr. R. Bendiksen.
- ⁸³ Davies B, Steele R. Challenges in Identifying Children for Palliative Care. *J Pall Care*. 1996; 12: 5-8.
- ⁸⁴ Dangel T. Pediatric Palliative Care — A Personal Perspective. *Eur J Pall Care*. 1998; 5(3): 86-91.
- ⁸⁵ Davies B, Collins J, Arcand R, Bhanji N, & Eng B. (October 1995). Hospice Care Plan: A Blueprint for the program of care Canuck Place. Submitted to the Board of Canuck Place, Vancouver, Canada. To obtain: Canuck Place, 1690 Mathews Avenue, Vancouver, BC V6J2T2, Canada, Tel: 604-821-1593.
- ⁸⁶ Raftery JP, Addington-Hall JM, MacDonald LD, Anderson HR, et al. A randomized controlled trial of the cost-effectiveness of a district coordinating service for terminally ill cancer patients. *Palliat Med*. 1996; 10(2): 151-161.