

NHPCO's Facts and Figures

Pediatric Palliative & Hospice Care in America

2015 Edition

*Sarah Friebert, MD
Conrad Williams, MD*

2015





Introduction

About this report

NHPCO's Facts and Figures about Pediatric Palliative and Hospice Care (PP/HC) in America provides an overview of the industry for providers, policy makers, funders and the media. The purpose of this report is three-fold:

1. to describe the current known state of PP/HC in the United States;
2. to identify children who may be in need of PP/HC support; and
3. to identify gaps in service.

What is palliative care?

According to the National Consensus Project for Quality Palliative Care, Third Edition (2013), *palliative care* is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care addresses physical, intellectual, emotional, social, and spiritual needs throughout the continuum of illness. Palliative care also facilitates patient autonomy, access to information, and choice.

Features that characterize the palliative care philosophy and its delivery are outlined in Table 1.

What is hospice care?

Considered the model for quality compassionate care for people facing a life-limiting illness, hospice provides expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is also provided to the patient's loved ones.



Hospice focuses on caring, not curing. In most cases, care is provided in the patient's home. Care may also be provided in freestanding hospice centers, hospitals, nursing homes, and other long-term care facilities. Hospice services are available to patients with any terminal illness or of any age, religion, or race. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.¹ A formal definition of hospice care can be found under Section 1861(dd)(1) of the Social Security Act: www.ssa.gov/OP_Home/ssact/title18/1861.htm.²

Table 1. Features of the Palliative Care Philosophy¹

- Care is provided and services are coordinated by an interdisciplinary team.
- Patients, families, palliative care providers, and non-palliative health care providers collaborate and communicate about care needs.
- Services are available concurrently with, or independent of, curative or life-prolonging care.
- Patient and family desires for peace and dignity are supported throughout the course of illness, during the dying process, and after death.

¹NHPCO Facts and Figures: Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization, October 2014.

²Social Security Act, Section 1861(dd)(1). United States Social Security Administration.



What is pediatric palliative/hospice care?

PP/HC is both a philosophy and an organized method for delivering competent, compassionate, and consistent care to children with chronic, complex and/or life-threatening conditions, as well as their families. PP/HC is planned and delivered through the collaborative efforts of an interdisciplinary team with the child, family, and caregiver(s) as its center. PP/HC is provided along with concurrent disease-modifying therapy when disease-modifying therapy is appropriate, or as the main focus of care when disease-modifying therapies are no longer effective and comfort is of utmost importance.

Effective management of pain and other distressing symptoms, along with psychosocial care, spiritual care, and decision-making guidance, are critically important beginning at diagnosis and continuing throughout the course of a child's life and beyond. Therapies take a holistic approach, assisting children and families in fulfilling their unique physical, psychological, educational, social and spiritual goals while remaining sensitive to developmental, personal, cultural and religious values, beliefs and practices.

The American Academy of Pediatrics released a policy statement on PP/HC in 2013, outlining core commitments of the discipline. These core commitments are presented in Table 2.³

How PP/HC is unique

Children with palliative care needs range in age from prenatal to young adult. In fact, some adults over the age of 21 are still considered part of this population because they have conditions monitored by pediatric subspecialists or have developmental and/or physical challenges that are better served by pediatricians. PP/HC teams must thus be able to care for patients with wide-ranging diagnoses and disease trajectories while providing developmentally-appropriate palliative care services. There are significant differences in what constitutes effective care for adult versus pediatric patients. These differences can occur in a number of dimensions, including:

- trajectories of illness,
- effective pain/symptom management interventions,
- clinical models of care delivery,
- funding mechanisms,
- research paradigms,
- educational initiatives,
- communication strategies,
- ethical concerns, and
- staffing ratios and management.

Table 2. Core Commitments of PP/HC³

- Being patient centered and family engaged
- Respecting and partnering with patients and families
- Pursuing care that is high quality, readily accessible and equitable
- Providing care across the age spectrum and life span, integrated into the continuum of care
- Ensuring that all clinicians can provide basic palliative care and consult PP/HC specialists in a timely manner
- Improving care through research and quality improvement efforts

³American Academy of Pediatrics, Section on Hospice and Palliative Medicine and Committee on Hospital Care. Pediatric Palliative Care and Hospice Care Commitments, Guidelines and Recommendations. *Pediatrics* 2013;132:966-972.



Epidemiology



Reliable statistics for children who receive PP/HC services remain difficult to parse from existing sources. It is also difficult to characterize children who might be appropriate or eligible for services because this characterization is a moving target. Variations in chronological, definitional, and prognostic criteria, as well as accessibility to established programs, hinder accurate descriptions of this population. For example, most available epidemiologic data focus on *children who die*, those with *complex chronic conditions (CCC)*, or *children with special health care needs (CSHCN)*. In contrast, PP/HC programs focus on nomenclature such as *life-limiting conditions (LLC)* or *life-threatening conditions (LTC)*, and the overlap among these categories is not easily defined.

Another issue is age: different sources stratify epidemiologic data on death and disease into different categories, lumping patients who are 19 and under, under 21, or 15-24 years of age into separate groups. PP/HC programs, on the other hand, may enroll patients up to 18 years, up to 21 years, or into adulthood if diagnosed with a pediatric condition or followed by a pediatric provider. Despite these limitations, a growing body of evidence allows an increasingly meaningful picture to emerge.

Total Deaths

According to the Centers for Disease Control and Prevention's most recent Annual Summary of Vital Statistics, in 2013 there were nearly 2.6 million deaths (2,596,993), representing the lowest annual age-adjusted rate to date: 7.3 deaths/1,000 US standard population. Children aged 0-19 years accounted for 1.6% of all deaths in 2013 with 42,328 total deaths, a number that continues to decline. Fifty-five percent of childhood deaths in 2013 occurred in infancy and approximately two-thirds of infant deaths occurred in the neonatal period. With 23,440 deaths, the infant mortality rate in 2013 was 5.96 per 1000 live births, a decline from 6.87 in 2005. Infant mortality rates for non-Hispanic black mothers, however, remain more than double those of non-Hispanic white and Hispanic mothers.⁴



⁴Osterman MJ, et al. Annual summary of vital statistics: 2012-2013. *Pediatrics* 2015; 135(6).



Causes of Death

The leading causes of death in infants are congenital malformations/chromosomal abnormalities and disorders related to short gestation and low birth weight (LBW).⁴ A list of causes is shown in Table 3. In forecasting which infants may be appropriate for PP/HC programs, etiology may also be examined by focusing on CCC. Among infants with CCC, causes of death are grouped differently (Table 3): cardiovascular, congenital/genetic, respiratory, and neuromuscular.

In 2013, there were 18,888 deaths in children ages 1-19 years, representing a death rate of 24 per 100,000. This is a significant decrease from a rate of 32.2 per 100,000 in 2005. Causes of death in 2013 for this age group were accidents, suicide, malignancy, congenital malformations/deformations and chromosomal anomalies, and heart disease. Malignant neoplasms remain the leading cause of disease-related death in childhood, and children between the ages of 15 and 19 years represent the majority of deaths (9,480) in this cohort (Table 3). Grouping cause of

death for this cohort with CCC, the causes in descending order are malignancy, neuromuscular (including neurologic and neurodegenerative), and cardiovascular.⁴

For the pediatric population as a whole, total preventable deaths (unintentional injuries and homicides) account for about one-fourth of deaths. Traditionally, PP/HC services have been targeted to the three-quarters of total deaths classified as not preventable.⁴ However, as these services have grown, they are better able to provide short term services, especially grief and bereavement support, to the cohort of patients and families affected by trauma or sudden serious illness and death.

The death rate for young adults (20-29 years old) remains stable. While non-accidental deaths are the predominant cause of mortality in young adults, deaths due to disease remain significant, especially for patients with CCC. This is at least partly explained by advances in life-extending medical treatment, which are postponing deaths that historically occurred earlier in childhood.⁴

Table 3. Causes of Death, Children Birth - 19 years

All Infants	Infants with CCC	All Children 1-19 Years	All Children 1-19 Years with CCC
1. Congenital malformations	1. Cardiovascular	1. Accidents	1. Malignancy
2. Short gestation / LBW	2. Congenital / genetic	2. Suicide	2. Neuromuscular*
3. Maternal complications	3. Respiratory	3. Assault	3. Cardiovascular
4. SIDS	4. Neuromuscular*	4. Malignancy	
5. Accidents/unintentional injury		5. Congenital malformations, deformations and chromosomal abnormalities	
6. Complications of placenta, cord, or membranes		6. Heart disease	
		7. Influenza and pneumonia	

* Includes static neurologic and neurodegenerative conditions



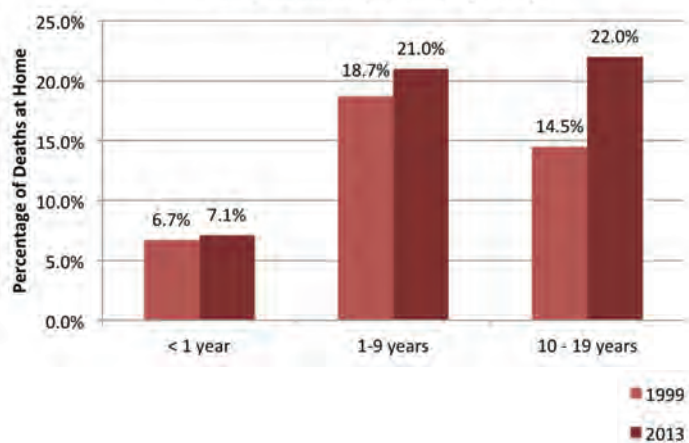
Location of death

As with adults, most children are still dying in the hospital, and most in an intensive care unit (ICU) setting. In a prospective, observational cohort study of all patients served by six hospital-based pediatric palliative care programs, 44.6% of patients were cared for in a home or hospice facility. Most patients (62%) who died did so in a hospital setting while 36.6% died at home or in a hospice facility.⁵ While the majority of pediatric patients are still dying in the hospital or emergency department, an increasing number of patients are dying at home. In a study by Feudtner of children under 20 years of age dying with CCC, the percentage of deaths occurring at home increased from 10.1% to 18.2% over a 15-year period.⁶

Changes in technology and payer/reimbursement structures have created a shift such that more complex medical regimens are increasingly used in home settings. This, in turn, results in an increased residential population of medically fragile children who could die at home at any time. The previously cited Feudtner study also showed a trend toward fewer hospital deaths over time. From 1999 through 2003, 80.1% of children died in hospitals versus 85.7% hospital deaths from 1989 through 1993. Moreover, as the overall number of deaths decreased (not shown), the proportion of deaths at home generally increased (Figure 1).^{6,7}

A further breakdown of the data reveals that the odds of dying at home are significantly smaller for black and Hispanic children. Geography also matters, as death at home is more likely in the West versus in the Northeastern United States.⁶

Figure 1. Deaths at home, by age group?⁷



An important point is that these data do not indicate directly whether children are dying at their (or their family's) preferred location; death at home is not always the most preferable because the hospital often becomes a second home for children with LTC or CCC, and many factors may contribute to a family's decision to remain in the hospital.

In a cross-sectional study of parents who lost a child to cancer, advanced planning for location of death was associated with increased deaths at home and decreased hospital admissions in the last month of life. Parents were more likely to plan for location of death when home care services were involved. For children who died in the hospital, those with advance care planning were more likely to die on the general ward rather than in the ICU, and less likely to be intubated in the last 24 hours of life. Importantly, parents who planned a location for their child's death were more likely to be comfortable with the setting of the death and less likely to have preferred a different location.⁸

⁵Feudtner, et al. Pediatric palliative care patients: a prospective multicenter cohort study. *Pediatrics* 2011; 127: 1094-1101.

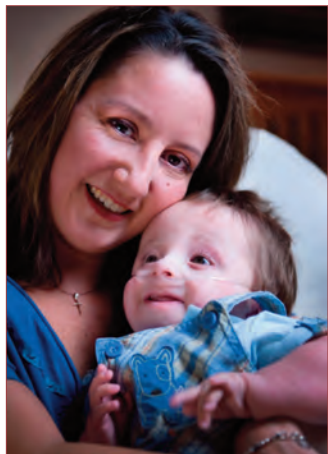
⁶Feudtner C, et al. Shifting place of death among children with complex chronic conditions in the United States, 1989-2003. *JAMA* 2007; 297(24): 2725-32.

⁷Centers for Disease Control and Prevention, National Center for Health Statistics. Multiple Cause of Death 1999-2013 on CDC WONDER Online Database, released 2015. Data are from the Multiple Cause of Death Files, 1999-2013, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed at <http://wonder.cdc.gov/mcd-icd10.html> on Jun 18, 2015.

⁸Dussel V, et al. Looking beyond where children die: determinants and effects of planning a child's location of death. *JPSM* 2009; 37(1): 33-42.



Eligibility for PP/HC Services



To determine baseline and projected growth for PP/HC service planning, programs generally look at 2 sources of data: children who are medically fragile enough to benefit from palliative care – e.g. those with CCCs and/or life-shortening conditions – and children who die. Projections from these two populations can help inform service design and staffing.

As within the young adult population, the overall prevalence of children with life-threatening conditions (LTC) is increasing due to advances in pediatric medical/surgical care. The overall number of deaths in children with CCC declined between 1989 and 2003.⁶ In other words, children with chronic illness and complex health care needs are living longer. These children require creative approaches to delivery of care coordination and PP/HC services over a longer term.

Data from a 2001 study by the Children's International Project on Palliative/Hospice Services (ChiPPS; now the Children's Project on Palliative/Hospice Services) estimated that on any given day 5,000 children with CCC were in the last 6 months of life. ChiPPS also estimated that 8,600 children would be eligible for palliative care services on any given day. Only 5,000 of the 53,000 children who died that year received hospice services, however, and usually only for a brief period of time.⁹

Due to the complexity of care involved, children with LTC/CCC are uniquely poised to benefit from PP/HC programs. According to the US Department of Health and Human Services, the number of children with special health care needs continues to increase. Overall, 15.1% of US children ages 0-17 (11.2 million children) are in this category; in American households, 23% have one or more CSHCN, 57% have two or more chronic health conditions, 68% have difficulty with at least one bodily function and 60.5% have difficulty participating in any activity. PP/HC services may not be appropriate for the majority of these children because their medical conditions may be relatively mild and stable. Despite this, 27% have conditions that affect their activities usually, always, or a great deal and potentially could benefit from PP/HC.¹⁰

In a study of childhood mortality in Washington state from 1980 to 1997, the percent of infant deaths from chronic conditions rose from 31% to 41%.¹¹ The previously cited study of patients with CCC who died before their 20th birthday between 1989 and 2003 revealed that 22.1% were due to CCC and 57% were less than 1 year of age.⁶ While most patients with CCC do not die in childhood, they have a 15-fold higher mortality when hospitalized,¹² and their death rate is dropping more slowly than that of age-matched unaffected children.¹¹

In a recent retrospective cohort analysis of patients hospitalized at 28 locations across the US, children with a chronic condition affecting two or more body systems accounted for 19% of all patients, but approximately half of both patient days (48.9%) and hospital charges (53.2%) in 2009. These 28 hospitals saw a median increase of 35.6% in number of patients with chronic conditions over the five year period of the study.¹³

⁹National Hospice and Palliative Care Organization. ChiPPS White Paper: A call for change: recommendations to improve the care of children living with life-threatening conditions. October 2001.

¹⁰US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2009-2010*. Rockville, Maryland: US Department of Health and Human Services.

¹¹Feudtner C, et al. Pediatric deaths attributable to complex chronic conditions: a population-based study of Washington state, 1980 to 1997. *Pediatrics* 2000; 106: 205-09.

¹²Simon et al. Children with complex chronic conditions in inpatient hospital settings in the United States. *Pediatrics* 2010; 126(4): 647-55.

¹³Berry JG, et al. Inpatient growth and resource use in 28 children's hospitals: a longitudinal, multi-institutional study. *JAMA Pediatrics* 2013 Feb; 167(2): 170-7.



Pediatric Program Demographics, Service Availability and Usage

PP/HC provision can be grouped into four basic models (outlined in Table 4), which can be combined to provide a continuum of care in any community:

1. Hospital-based programs;
2. Free-standing pediatric hospice facilities;
3. Hospice-based programs; and
4. Community agency or long-term care facility-based programs.

Table 4. Models of PP/HC Provision

Model 1. Hospital-based programs

- Consultative services
- Primary medical management (rare)
- Designated PP/HC beds
- Designated PP/HC unit (rare)
- Outpatient services
- Pediatric unit or department as part of larger adult hospital

Model 2. Free-standing pediatric hospice facilities

- Few in US, many more internationally
- Persistent questions of long-term financial sustainability
- Currently require heavy reliance on philanthropic support

Model 3. Hospice-based programs

- Dedicated PP/HC team
- Adult program with pediatric personnel or contracted expertise

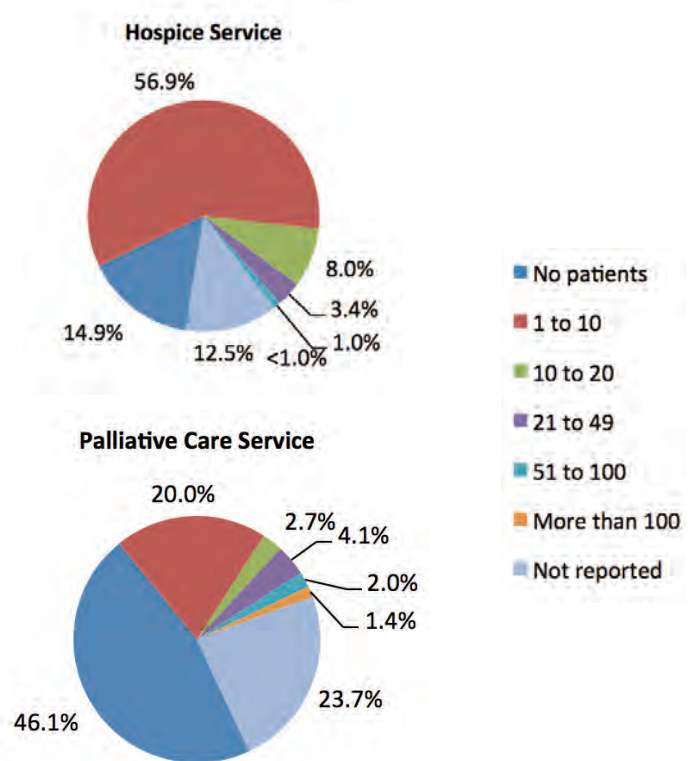
Model 4. Community agency or long-term care facility-based programs

Accurate information about availability of PP/HC programs is slowly growing. In a recent survey of children’s hospitals across the U.S., 69% reported having a palliative care team. Nearly 30% of the programs offer home visit services.¹⁴ However, such surveys are plagued by the problem of program definition since the spectrum of services in an institution that reports a PP/HC program may range from

a single, part-time unsupported but interested provider to a full-fledged PP/HC team. Despite these limitations, guidance is available.

In 2007, NHPCO conducted its second survey on pediatric services to member-providers. Overall, 78% of responding hospices reported that they serve pediatric patients, and 36.6% have a formal pediatric program in place. Of those without a dedicated pediatric team, 21.7% have specialized staff providing only pediatric services. Hospices providing pediatric services most often have between 1 and 20 pediatric patients per year. Palliative care services provided to pediatric patients ranged from 0 to 10 patients in the majority of cases (Figure 2).

Figure 2. Average number of pediatric patients served per year, by type of hospice



¹⁴Feudtner, et al. Pediatric palliative care programs in children’s hospitals: a cross-sectional national survey. *Pediatrics* 2013 Dec; 132(6): 1063-70.



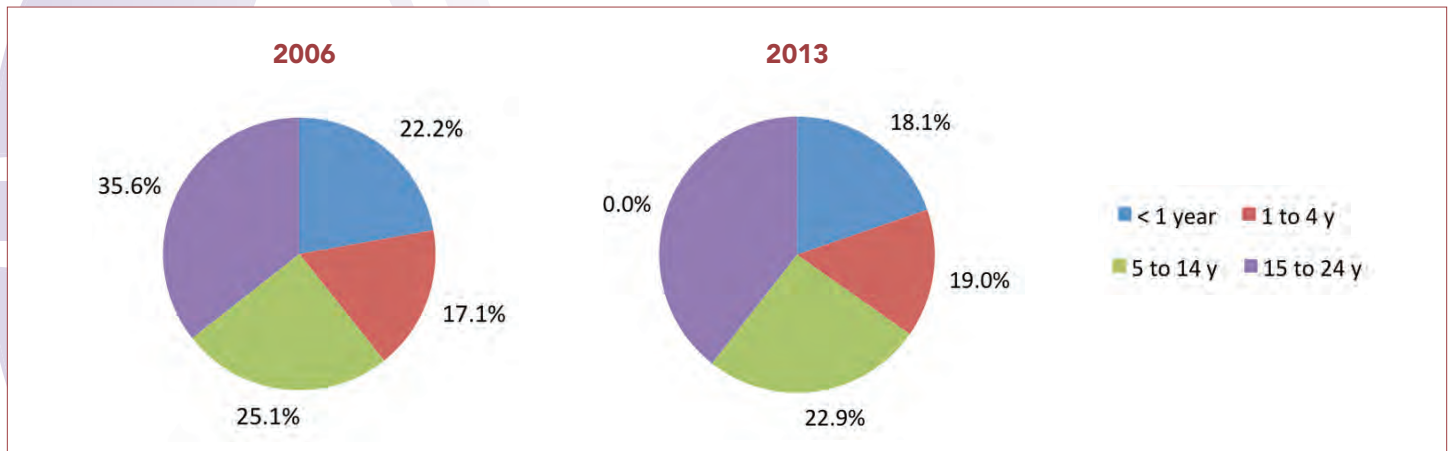
Although no formal survey on pediatric services has been performed since 2007, data from NHPCO’s 2013 National Summary of Hospice Care shows that 14.1% of participating agencies have formal pediatric palliative care services with specialized staff. Comparing the 2013 National Summary of Hospice Care to that from 2006, the percentage of younger hospice patients has not changed substantially, even with the increase in total number of patients cared for by hospice. Patients younger than 35 years of age made up only 0.8% of those served in 2013. The proportion of younger patients receiving services is unchanged even with significant increases in both the number of patients served by hospice and in the number of hospice locations nationwide. The distribution of pediatric patients served by age is shown in Figure 3.¹⁵

A cohort study published by Feudtner et al. in 2011 provides further insight into the demographic and clinical characteristics of patients served by PP/HC teams. The cohort of 515 patients from six hospital-based pediatric palliative care teams in the US and Canada were enrolled over a 3-month period in 2008. Highlights of the study are provided in Table 5.

Table 5. Results of Cohort Study¹⁶

Measure	Result
Age	<1yo: 17.1% 1-19yo: 67.5% >19yo: 15.5%
Most common primary diagnosis	Genetic/congenital 41% Neuromuscular 39% Malignancy 19.8%
Medical Technology Use	None 20% Feeding Tube 59.6% Central line 22% Tracheostomy 10% Ventilator dependent 9%
Mean number of medications	9.1
Mortality at 12 month follow up	30.3%
Median time from consult to death	107 days

Figure 3. Age of pediatric hospice patients served, 2006 (n=697) vs. 2013 (n=331)



¹⁵National Hospice and Palliative Care Organization. NHPCO 2013 National Summary of Hospice Care, November 2014.

¹⁶Feudtner, et al. Pediatric palliative care patients: a prospective multicenter cohort study. *Pediatrics* 2011; 127: 1094-1101.



Payment Models

Although payment and reimbursement for PP/HC remains a complex issue, passage of the Patient Protection and Affordable Care Act (ACA) in 2010 carries great potential for change. Section 2302 of the ACA, the concurrent care for children requirement, mandates that children who are in a state Medicaid or Children's Health Insurance Program who are eligible for hospice care also continue to be eligible to receive coverage for curative, disease-directed therapies. The passage of this section of the ACA is an important first step in addressing the pediatric palliative care needs

of children nearing the end of life. Section 2302 is a required mandate for states, although some states have had challenges in implementing the provision. Collaboration at the state level, among providers, policymakers, and families, in securing the appropriate care and resources for this patient population is paramount. NHPCO has developed a concurrent care implementation toolkit as a resource for hospice organizations and individuals caring for children who would benefit from PP/HC services. The toolkit can be accessed at www.nhpco.org/pediatrics.

Cost-Related Outcomes of PP/HC

Though lagging far behind adult data, recent information about cost neutrality and even savings provided by PP/HC programs (when care is integrated early in the illness trajectory) is accumulating. Preliminary data from Partners for Children, a community-based PP/HC benefit in California, showed promising results. In contrast to the concurrent care for children requirement of the Affordable Care Act, this benefit provides access to comprehensive in-home PP/HC services as early as the time of diagnosis. Results from a 2012 study by the UCLA Center for Health Policy showed an 11% (\$1,677) reduction in monthly cost per patient, 32% reduction in average number of days spent in the hospital, and reduced stress and sleep disturbance with increased confidence in ability to care for a child by the primary caregivers, compared to patients who did not receive in-home services.¹⁷ One home-based PPC/HC

program showed that enrollment in services was associated with decreased hospital length of stay and total healthcare charges for patients with non-cancer diagnoses.¹⁸



¹⁷Ghans D, et al. Better outcomes, lower costs: palliative care program reduces stress, costs of care for children with life-threatening conditions. UCLA Center for Health Policy Research, August 2012.

¹⁸Postier A, et al. Exposure to home-based pediatric palliative and hospice care and its impact on hospital and emergency care charges at a single institution. *J Palliat Med.* 2014 Feb; 17(2): 183-8.



Discussion

The overall goal for programs planning PP/HC services is to identify children who may benefit from their support. This identification cannot be done simply based on diagnosis or prognosis; each child and family is affected uniquely both medically and psychosocially by a chronic illness or injury. Nevertheless, careful analysis of national and local statistics and trends can provide guidance for estimating volume. Trigger lists detailing criteria for palliative care assessments, such as the one developed by the Center to Advance Palliative Care (CAPC), can be beneficial to providers.¹⁹ Statistics can also help guide design and scope of services. Because of variability in diagnostic and chronologic classification in existing information, data should be gleaned from multiple sources in attempt to plan for PP/HC program development and service provision.

Preventable and/or sudden deaths should not necessarily be excluded from PP/HC services, depending on program scope and resources. A fairly robust estimate of potential volume can be made from subtracting sudden/traumatic deaths from the total regional deaths to arrive at a number appropriate for hospice care. This number, however, does not include the proportion of sudden/traumatic deaths that may be appropriate for palliative care services; excluding these patients also excludes a significant percentage of children with CCC/LTC/SHCN who are appropriate for palliative care services under most program definitions.

Though the reasons for the increasing prevalence of home deaths and the racial and ethnic disparities are multifactorial and not clearly understood, it is increasingly important that all patients have access to community resources, such as pediatric hospice programs, that can provide care regardless of location or socioeconomic status.

Implementation of the concurrent care portion of the ACA is an immense milestone in the field. PP/HC teams no longer must wait for families to forgo curative treatment in order to become involved in care. This obviates the expectation that patients and families must fit the traditional Medicare hospice benefit. Earlier involvement allows the team to help the family better navigate both the health care system and the illness journey and make important decisions with accurate information and support. Though state-by-state adoption of the concurrent care provision is still spotty, a significant burden can also be lifted from families as they can pursue disease-directed therapies while also utilizing the extensive and crucial support structures that come with involvement of PP/HC services. Significant barriers to access remain that must be addressed. Now, more than ever, it is important that PP/HC organizations collaborate to advocate for implementation of concurrent care. As the patient population grows, it is imperative that expansion of PP/HC services is done efficiently and effectively, with emphasis on educating the medical community about the benefits of PP/HC. It is also crucial that the field dedicate itself to extensive data collection that will lead to development of a robust evidence base supporting the role of PP/HC services within the pediatric healthcare system. Collaborative efforts to share best practices are crucial to expanding the field.

For in-depth discussion of diagnostic categories, selection of appropriate children for palliative care, interdisciplinary team members and roles, and specific differences between pediatric and adult P/HC, please refer to the National Hospice and Palliative Care Organization's (NHPCO) Standards of Pediatric Palliative Care and Hospice, www.nhpco.org/pediatrics.

¹⁹Friebert S, Osenga K. Pediatric Palliative Care Referral Criteria. (<http://www.capc.org/tools-for-palliative-care-programs/clinical-tools/consult-triggers/pediatric-palliative-care-referral-criteria.pdf>)



Glossary/Nomenclature

ACA: *The Affordable Care Act* is a federal statute signed into law in March 2010. Signed under the title of The Patient Protection and Affordable Care Act, the law included multiple provisions that would take effect over a matter of years, including the expansion of Medicaid eligibility.

CCC: *Complex Chronic Conditions* are medical conditions that can reasonably be expected to last at least 12 months, unless death intervenes, and either to involve several different organ systems or to involve one organ system severely enough to require specialty pediatric care, with a likelihood of some period of hospitalization in a tertiary care center.

CSHCN: *Children with Special Health Care Needs* have or are at risk for a chronic physical, developmental, behavioral or emotional condition and also require health and related services of a type or amount beyond that required by children generally.

ICU: *Intensive Care Unit* is a specialized section of a hospital that provides comprehensive and continuous care for persons who are critically ill and who can benefit from treatment.

LBW: *Low Birth Weight* is defined as a birth weight of a live born infant of less than 2,500 g (5 pounds 8 ounces) regardless of gestational age.

LLC: *Life-limiting Conditions* are conditions in the pediatric population with which the child is not expected to live to adulthood.

LTC: *Life-threatening Conditions* are conditions that are very serious, pose a threat to the child's well-being and where prognosis is questionable.

PP/HC: *Pediatric Palliative/Hospice Care* is both a philosophy and an organized method for delivering competent, compassionate, and consistent care to children with chronic, complex and/or life-threatening conditions and their families.

©2015 National Hospice and Palliative Care Organization.

All rights reserved, including the right to reproduce this publication or portions thereof in any form.

Suggested citation:

NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America. Alexandria, VA:
National Hospice and Palliative Care Organization, September 2014.

Questions may be directed to:

National Hospice and Palliative Care Organization
Attention: Research Department or ChiPPS
Phone: 703.837.1500
Web: www.nhpco.org
Email: info@nhpco.org

Additional resources on pediatric palliative and hospice care are available at www.nhpco.org/pediatrics.