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CATALYST
CENTER
IMPROVING FINANCING OF CARE
for Children & Youth
WITH SPECIAL HEALTH CARE NEEDS

Financing Pediatric Palliative and Hospice Care Programs

An Important but Underutilized Service for Children with Life-limiting Conditions

In this article, we focus on financing mechanisms for pediatric palliative and hospice care programs. Pediatric palliative care is an important but underutilized service that focuses on complex pain and symptom management and interventions to improve the quality of life for children with life-limiting conditions and their families.[1] Palliative care differs from traditional hospice services in that curative or life-prolonging treatments are often provided alongside palliative services throughout the course of the illness or condition and there are no time constraints associated with it. Hospice care, which like palliative care includes medical, emotional and spiritual supports, is provided to patients who are terminally ill (generally with a life expectancy of six months or less).

When seeking palliative and hospice care for their child with a life-limiting condition, one of the primary barriers families come up against are gaps and limitations in insurance coverage and financing. In this article, we introduce pediatric palliative and hospice care and discuss some of the challenges around financing these services for children with life-limiting conditions, who comprise a subpopulation of children and youth with special health care needs (CYSHCN).[2] Next, we provide some state-specific examples of noteworthy strategies for financing pediatric palliative care programs that can be replicated.

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[1] Children with life-limiting conditions are a subpopulation of CYSHCN whose diagnoses cause them to have or put them at risk for a limited life expectancy. A few examples of life-limiting conditions in children include cystic fibrosis, muscular dystrophy, cancer, and congenital anomalies. Many of these children may eventually need end-of-life (EOL) or hospice care but may live for many years with their chronic conditions before reaching that point.

[2] As defined by the federal Maternal and Child Health Bureau (MCHB), children and youth with special health care needs (CYSHCN) are those from birth to age 21 who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and need health and related services of a type or amount beyond that required by children generally.

Palliative and hospice care: What's the difference?[3]

	Palliative Care	**Hospice**
Timing	There are no restrictions on when palliative care can begin. Ideally, it is initiated as early as diagnosis and continues throughout the course of the illness or condition.	Hospice benefits are typically covered by insurance only for people with terminal illness (usually defined as having a six-months-or-less life expectancy).
Payment	Coverage of palliative services varies widely across insurance sources. Palliative care services that are covered by medical insurance are billed for separately. Services that are part of many high quality palliative care programs are not considered medical care (such as family respite) and so are not typically covered by private health insurance. In addition to limited revenue from billing, philanthropic support (grants and donations) are important sources of funding.	Coverage of hospice services also varies across insurance coverage sources, but are typically administered through a hospice agency. As hospice is considered "all-inclusive," items are not billed for separately. Many hospice programs are subsidized or covered by Medicare or through Medicaid waiver programs. Philanthropic support (grants and donations) are also important sources of funding.
Treatment	Palliative care can begin as early as diagnosis; thus, it can provide services, comfort and support at any stage of the patient's illness or condition, alongside curative or life-prolonging treatment.	Hospice care usually focuses on providing physical and emotional comfort as the patient nears the end of his or her life. No curative or life-prolonging treatments are provided under hospice.

Introduction to Palliative Care

Palliative care can improve quality of life, optimize function, and minimize the physical suffering and emotional hardship faced by children with life-limiting conditions and their families. Palliative care is usually provided by a multidisciplinary team working in conjunction with clinicians treating the primary diagnosis and focuses

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[3] Table adapted from "Hospice vs. Palliative Care," by Ann Villet-Lagomarsino. Educational Broadcasting Corporation/Public Affairs Television, Inc. Available from the National Caregivers Library. Accessed April 4, 2011 from http://www.caregiverslibrary.org/Default.aspx?tabid=375.

primarily on complex pain and symptom management. It also provides holistic support services to families as they learn about their child's needs and prognosis, become adept at navigating the medical system, and formulate strategies for making difficult decisions. Unlike hospice care, which is provided near the end of life, many model palliative care programs take an integrated, interdisciplinary approach to care provision, starting as early as when the child is diagnosed and continuing for months or even years. In addition to the obvious benefits to the child with a life-limiting condition and his or her family, palliative care has been shown to decrease both hospital admissions and average lengths of stay in medical facilities for this pediatric patient population.[4]

Barriers to Pediatric Palliative Care

In the U.S. annually, about 500,000 children experience life-limiting conditions expected to eventually lead to premature death.[5] While their conditions may cause them to have or be at risk for a shorter life expectancy, many of these children live for long periods of time - sometimes many years. Unlike in adults, life-limiting conditions in children are commonly neurological or genetic in origin. This results in often protracted and unpredictable clinical trajectories and prognostic uncertainties. Thus, many children with life-limiting conditions could benefit from pediatric palliative care services that can be provided alongside curative or life-prolonging treatment, starting at diagnosis. However, Children's Hospice International (or CHI, a non-profit organization focusing on integrating hospice services into routine pediatric medicine) asserts that both palliative care and hospice services are often unavailable and/or insufficient to adequately meet the needs of children with life-limiting conditions and their families.[6] Many of the benefits of palliative care are also offered through hospice, and the financing mechanisms for hospice care are more clearly defined than for palliative care. However, there are barriers to children and families accessing them through hospice because of the restrictions in coverage and financing policies for hospice services, which include a general requirement that the patient have a six-months-or-less life expectancy and stop receiving curative treatments. These restrictions are directly counter to optimal palliative care for children because they do not take into account the medical needs or preferences of the child and his or her family due to the nature of life-limiting conditions in children. Cultural barriers in the context of these restrictions also inhibit optimal palliative care. It can be very difficult for both

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[4] Children's Hospice and Palliative Care Coalition. "The Waiver." September 2008. Accessed March 25, 2011 at http://www.childrenshospice.org/benefit/waiver/.

[5] Himelstein BP, Hilden JM, Boldt AM, and Weissman D. Pediatric Palliative Care. New England Journal of Medicine. 2004; 350:1752-62.

[6] Children's Hospice International. "Children's Hospice International Program for All-Inclusive Care for Children and their Families (PACC)." Accessed March 24, 2011 at http://www.chionline.org/programs/.

clinicians and families to make the decision to stop cure-directed treatment, or to give up hope for their patient or child's improvement in order to access services through hospice.

Financing Mechanisms for Pediatric Palliative Care

According to the National Hospice and Palliative Care Organization (NHPCO), payment and reimbursement for pediatric palliative and hospice care is complex.[7] Children without insurance are dependent on out-of-pocket payment by families and philanthropic support received by nonprofit organizations, including hospitals, for both palliative and hospice care. Public benefit programs play an important role in financing pediatric palliative and hospice care. Medicare is the primary payer for hospice services in general but not for children. Medicare has few pediatric enrollees and the hospice benefit it offers is not tailored to the needs of children with life-limiting conditions. Medicaid can cover both pediatric palliative and hospice care services through waiver programs, but the services provided vary by state and can be limited in scope. Moreover, hospice benefits under Medicaid have traditionally not included an option for concurrent curative or life-prolonging treatment. Now, under the Affordable Care Act of 2010, children with life-limiting conditions enrolled in Medicaid or CHIP may receive hospice care concurrently with these types of treatment, but only if they have a life expectancy of six months or less.[8]

Insured children who do not qualify for public benefit programs also face obstacles in accessing pediatric palliative and hospice care.[9] According to NHCPO, most private insurers do not cover curative or substantive palliative services in their hospice benefit policies, assuming they offer them. Additionally, palliative care is largely comprised of "supportive" (sometimes called "wraparound") services which are infrequently covered by insurance.[10] State-mandated benefit laws tend to center on hospice services in the last six months of life, not on palliative care from the point of diagnosis until end-of-life care is needed.[11] A review of current state mandated benefit

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[7] Friebert S. "NHPCA Facts and Figures: Pediatric Palliative and Hospice Care in America." National Hospice and Palliative Care Organization. April 2009. Accessed March 28, 2011 at http://www.nhpco.org/files/public/quality/Pediatric_Facts-Figures.pdf

[8] The Patient Protection and Affordable Care Act, Section 2302 "Concurrent Care for Children".

[9] NHCPO. "Guidance on New Hospice Benefits for Terminally Ill Children." Press Release. September 13, 2010. Accessed March 28, 2011 at http://www.nhpco.org/i4a/pages/index.cfm?pageid=5759

[10] Torkildson C. "Models of Pediatric Hospice and Palliative Care in the United States." Children's Project on Palliative/Hospice Services (ChiPPS) E-Newsletter. Updated August 11, 2010. Accessed March 28, 2011 at http://www.nhpco.org/files/public/Chipps/ChiPPS_enews-19_May_2010.pdf

[11] State-mandated benefits for hospice exist in Arizona, Colorado, Hawaii, Kentucky, Massachusetts, Maryland, Maine, Michigan, Nevada, New York, Virginia, and Washington. Source: Health Insurance Mandates in the States, 2010. Catalyst Center Website. Available at http://www.hdwg.org/catalyst/health-insurance-mandates-in-the-states-2009

laws for hospice care by Catalyst Center staff found that in general, they only apply to individuals who are terminally ill and do not include those at risk for a limited life expectancy. In some cases, a few palliative services are included under the law, but under limited circumstances. Thus, private insurers continue to have the option of excluding many palliative services from their benefit packages. Self-funded plans - which account for about half of private insurance plans nationally - are not required to adhere to state-mandated benefit laws. So even if robust pediatric palliative services fall within a state-mandated benefit, self-funded plans may choose not to offer them.

As illustrated above, while financing mechanisms for pediatric hospice care services are more defined, the existing models of financing pediatric palliative care programs have substantial limitations and are relatively scarce. However, several states have taken advantage of the options available and designed creative approaches to ensure the adequate provision of palliative services to the children who need them. We've highlighted two primary financing approaches for pediatric palliative care below: a Medicaid waiver program in Florida and California, and a state-funded program in Massachusetts.

Funding Pediatric Palliative Care Programs with a Medicaid Waiver

Medicaid is funded by a federal-state partnership; in order to receive federal funds, states must comply with federal Medicaid regulations. A waiver is permission from the federal government for a state to disregard one or more of these rules, under specific conditions. Home and Community-Based Service (HCBS, also known as 1915) waivers allow states to offer benefits that Medicaid does not normally cover so that enrollees can remain in their homes and communities instead of receiving care in an institutional setting such as a hospital or nursing home. These benefits often include wrap services such as specialized home health care, case management, respite care and family support services. HCBS waivers can also expand the income eligibility for Medicaid, so patients who qualify for an institutional level of care but whose families make too much money to qualify for Medicaid can enroll in the waiver and receive benefits.

Partners in Care: Together for Kids - Florida

In 1999, a study conducted in Florida found that 50% of the state's hospice programs felt their services did not adequately meet the needs of terminally ill children and their families. Additionally, only half of the 36 hospices surveyed provided a full pediatric hospice program. All of these hospices were bound by the policies of the Medicaid hospice reimbursement regulation, which required hospice enrollees to have a six-months-or-less life expectancy and to stop curative treatments before they could access hospice benefits. Rolled out in 2005, Partners in Care: Together for Kids (PIC:TFK) became the first Medicaid waiver program in the United States in which children with life-limiting illnesses could receive palliative care concurrently with curative treatment.

PIC: TFK is a 1915(b) Medicaid waiver program operated under the authority of Children's Medical Services (CMS), Florida's Title V program for Children with Special Health Care Needs (CSHCN). PIC:TFK is a demonstration program of the Children's Hospice International Program for All Inclusive Care for Children (CHI PACC) model, which has become nationally recognized in addressing the needs - both palliative and curative - of children with life-limiting conditions and their families. PIC:TFK is implemented through a partnership between CMS, Florida's Agency for Health Care Administration (AHCA), and hospices throughout the state. Care coordinators with the Children's Medicaid Services Network (or CMSN, the Medicaid managed care provider under CMS) identify eligible children and enroll them in PIC:TFK. Once enrolled, the child receives home- and community-based palliative services provided by hospice staff specially trained in pediatric palliative care. These services are based on the individual child and family's care plan, which is regularly reassessed and updated. AHCA then provides reimbursement to the hospices.

Florida children qualify for PIC:TFK in any stage of their life-limiting illness: they may be newly diagnosed, in the mid-stage of the illness (receiving life-prolonging or curative treatments), or at the endstage, when treatment has failed. Children must be under age 21, enrolled in their regional CMSN, and qualify for Medicaid, CHIP, Florida KidCare (Title XXI) or CMS Safety Net funding to participate in PIC:TFK.

The program's mission is "...to enable children with life-limiting conditions and their families to have an enhanced quality of life through a combination of medical and supporting services that are accessible, continuous, compassionate, comprehensive, culturally sensitive and family/caregiver centered." Within PIC:TFK, children and their families can receive pain and symptom management, patient and family counseling, expressive therapies like play, music, and art, specialized nursing care, psychosocial and spiritual therapy, respite care, volunteer services, and bereavement support. PIC:TFK aims to provide children and families a continuum of care that is consistent through transitions from the home to the hospital or other health facility, and to and from day care and school.

Surveys of enrolled families show high satisfaction with the program - about 91% of parents report they have had a satisfactory experience with PIC:TFK, and 94% of parents would recommend the program to other families of children with life-limiting conditions. As of January 2010, eligible children could access PIC:TFK services at eight sites across Florida: in Gainesville, Ft. Myers, Jacksonville, Lakeland, Miami, Pensacola, Sarasota, and St. Petersburg. PIC:TFK continues to expand throughout Florida, with five additional sites planning to roll out PIC:TFK services in Ft. Lauderdale, Naples, Ocala, Tallahassee, and Tampa.

Sources:

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Knapp CA, Madden VL, Curtis CM, Sloyer PJ, Huang IC, Thompson LA, and Shenkman EA. Partners in Care: Together for Kids: Florida's Model of Pediatric Palliative Care. Journal of Palliative Medicine. 2008: 11(9). P. 1212-1220.

Partners for Children - California

At San Diego Hospice in early March, the Comprehensive Care Management Programs (CCMP) celebrated their one-year anniversary of serving as the state's first provider of Partners for Children (PFC) services, a model of palliative care provision. Bringing a managed care approach to home-based, full-spectrum palliative care, PFC offers an alternative to hospitalizing children with life-limiting conditions. PFC is now available to eligible children in 3 counties throughout the state, with 4 more counties gearing up to participate. PFC also has plans to expand to several more counties over the next few months.

The PFC model is based on the idea that a continuum of care can be created by providing community-based hospice and palliative care services alongside curative treatment and that minimizing a child's use of out-of-home care settings can improve the health care experience for the child and his or her family. Within the PFC waiver program, pediatric patients receive palliative care in the comfort of their homes instead of in health care facilities (hospitals, pediatric nursing homes, etc.). Through collaboration with participating community hospice and home health agencies, PFC ensures children in the program receive pain and symptom management, services to improve their quality of life, and emotional support - all major aspects of comprehensive palliative care - in a consistent and coordinated manner. In addition to care coordination, specific services offered through PFC include respite care, child and family support counseling, expressive therapies such as art, music and massage, bereavement counseling, and family educational and training programs on aspects of their child's care. All of these supportive services aim to help families better manage their child's life-limiting conditions at home.

Children under 21 years of age with life-limiting conditions, who are enrolled in Medi-Cal (California Medicaid), qualify for California Children's Service (CCS, a state-funded health care program for children with "special medical needs" in low-income families)[12] and live in a county of California that is participating in PFC, are eligible for the PFC waiver. A range of conditions meet the diagnoses requirement for PFC eligibility, including cancer, cystic fibrosis, brain or head injuries, spinal muscular atrophy, Duchene's muscular dystrophy (dependent on a ventilator), intestinal problems with dependence on IV nutrition, liver or bowel transplant, heart defects or conditions, problems following a transplant, and leukodystrophies.

Children and their families may self-refer to the PFC program or may be referred by their primary care physician or by the CCS office directly. Once referred, CCS Nurse Liaisons work with the child's primary care physician to acquire the necessary medical documentation and forms required for enrollment. During the enrollment process, the child and/or parent will select a hospice or home health agency that will provide the PFC services. The CCS Nurse Liaison then connects the family to the care coordinator at the family's chosen agency, and service provision begins. 26 children with life-limiting conditions are currently enrolled in PFC, with the goal of increasing that number to 50 by September, 2011.

One mother's testimony of her PFC experience shows how the program can help the entire family of a child with a life-limiting condition. Her son, Tyler, has cerebral palsy. He was recently sick for five weeks, and through PFC, Tyler's mom was able to care for him in their home instead of admitting him to a hospital. PFC staff ensured Tyler and his family received home visits from health providers, called Tyler's doctors to follow up on his treatment regimen, and even helped Tyler's mom get things in order for Tyler to go back to school after his 5-week absence. Tyler's mother also noted that her entire family was impacted by Tyler's condition, but that they found support in the family counseling and art therapy offered by PFC. As this mother's story illustrates, PFC can greatly benefit not only enrolled patients, but entire families of children with life-limiting conditions.

For more information on the program, visit the Partners for Children website at http://www.californiapartnersforchildren.org/.

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[12] For a complete list of the eligibility requirements for CCS, visit the "Find Out if I Qualify" page on the CCS website at http://www.dhcs.ca.gov/services/ccs/Pages/qualify.aspx

Sources:

California's First Partners for Children Program Meets the Special Medical Needs of Chronically Ill Children in San Diego. March 1, 2011. PR Newswire. Accessed March 22, 2011 at http://www.prnewswire.com/news-releases/californias-first-partners-for-children-program-meets-the-special-medical-needs-of-chronically-ill-children-in-san-diego-117134343.html

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Partners for Children Flyer. California Department of Health Care Services. http://californiapartnersforchildren.org/PFCFlyer.pdf

Partners for Children Referring Physician Flyer. State of California Health and Human Services Agency and California Department of Health Care Services. Undated.

State-Funded Pediatric Palliative Care Programs

An alternative to financing pediatric palliative care programs through a Medicaid waiver is to fund them directly from the state budget. This is a viable option as it gives states more flexibility in designing a program to meet the specific needs of its residents. Unlike the Medicaid waiver programs discussed above, there is no federal match for a state-funded program.

Pediatric Palliative Care Network - Massachusetts

In April 2006, Massachusetts' health care reform legislation, "An Act Providing Access to Affordable, Quality, and Accountable Care," resulted in the establishment of the Pediatric Palliative Care Network program. The program is administered by the Massachusetts Department of Public Health, Division for Perinatal, Early Childhood and Special Health Needs, which is home to the state Title V Children & Youth with Special Health Care Needs Program.

The Pediatric Palliative Care Network (PPCN) program is designed to complement existing services to meet the needs of eligible children with life-limiting conditions and their families. These services are provided primarily in the home and are appropriate for children with a wide range of life-limiting conditions, even when cure remains a possibility. The PPCN program supports the child and family with services designed to achieve an improved quality of life by meeting the physical, emotional and spiritual needs experienced during the course of illness, death and bereavement.

As aptly described by the Canadian Hospice Palliative Care Association (2006), pediatric palliative care "is designed to enhance choice, relieve suffering, and ensure the best quality of care during living, dying and grieving." The Massachusetts PPCN program supports the child and family to accomplish these goals in accordance with their values, needs and preferences by providing access to a full range of consultative and direct care palliative services. The services complement those rendered by the child's primary care provider who retains professional responsibility for the child's plan of care. Examples of these services include but are not limited to skilled pain and symptom management, 24-hour on-call services, counseling for the child and family, spiritual care, advance care planning, referrals to other community services, short-term respite care, and bereavement care for the family.

Currently, the network of PPCN providers includes eleven licensed hospices throughout Massachusetts. Every participating hospice is skilled in pediatric palliative care. PPCN aims to enhance the quality of life and meet the physical, emotional, social and spiritual needs of children with life-limiting conditions and their families through providing a multitude of palliative services.

Unlike hospice care, admission to the PPCN is not prognosis-dependent. Also, unlike public benefit programs such as Medicaid and CHIP, eligibility is not determined based on a family's income level or insurance type or status. Potentially, any child up to the age of 19, living in Massachusetts and diagnosed with a life-limiting condition could take part in the program.

When the PPCN was first established, typical hospice benefits required that a child cease curative treatment in order to receive hospice. The pediatric hospice benefit was changed in September 2010 as part of the Affordable Care Act. It now allows children to pursue curative treatment, but they still must have a signed order from the physician that the child has a six-months-or-less life expectancy. For this reason, many children remain ineligible for hospice.

To take part in the PPCN program, a referral to a PPCN ¬contracted hospice must be made. A family can self-refer or the referral can come from the child's primary care provider (PCP), another health care provider, a state Department of Public Health program, another state or community agency, or a family caregiver. Once the referral has been made, the PPCN hospice goes through the necessary steps to ensure the child meets the eligibility requirements (he or she is under 19, lives in Massachusetts and has a potentially life-limiting condition). If the child is eligible, within 48 hours of the referral, a PPCN provider completes a full assessment of the child and family's physical, psychosocial, emotional and spiritual needs and bereavement risks. Then an individualized care plan is created to reflect those needs, and service provision begins.

Annual funding for the PPCN program is dependent upon the state budget allocation; it has ranged from a high in FY07 of $800,000 to a low of $786,444 in FY11. In FY10, the 4th year of the PPCN, the program served 227 children and their families, a 14% increase from the previous year.

For more information on the Massachusetts Pediatric Palliative Care Network, visit the PPCN program website at http://www.mass.gov/ppcn.

Source:

Jennifer Kenyon Bates, MEd. Director, Pediatric Palliative Care Network (PPCN). Massachusetts Department of Public Health. Personal Communication. 7 April 2011.

Conclusion

Palliative and hospice services are vitally important to relieving pain, managing symptoms and improving the quality of life for many children with life-limiting conditions, a subpopulation of children and youth with special health care needs. But these children and their families often face barriers to accessing them. The main challenges are the gaps and limitations in coverage and financing of pediatric palliative and hospice care programs. In particular, the wrap services and care continuum that characterize strong palliative care programs are infrequently covered by private insurance. Traditional hospice services under Medicare are designed to meet the needs of dying adults - not those of children with life-limiting illnesses who often have longer or unpredictable illness trajectories and unique psychosocial and developmental needs and who can benefit from palliative care services long before they either need or become eligible for end-of-life care. As demonstrated in the Florida, California and Massachusetts examples above, a pediatric palliative care program that addresses these considerations, incorporates a robust set of both medical and psychosocial interventions, and has flexibility around eligibility and payment source can make great strides in addressing the current problems and inadequacies in financing palliative and hospice care for children.

Interested in learning more from the provider perspective? View a YouTube video (http://www.youtube.com/watch?v=Udu-XywYWKo) of the work of the Pediatric Advanced Care Team (PACT) at Children's Hospital Boston. Dr. Joanne Wolfe, Palliative Care Director at Children's, discusses the benefits of interdisciplinary pediatric palliative care services to families of children with life-limiting conditions. This video was produced by kaiserhealthnews.org and is linked to with permission from the Henry J. Kaiser Family Foundation, a nonpartisan health care policy research organization unaffiliated with Kaiser Permanente.

For consumers, the National Institute of Nursing Research has produced a brochure describing palliative care: Palliative Care: The Relief You Need When You're Experiencing the Symptoms of Serious Illness (http://www.ninr.nih.gov/NR/rdonlyres/01CC45F1-048B-468A-BD9F-3AB727A381D2/0/NINR_PalliativeCare_Brochure_508C.pdf)

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About the Catalyst Center

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Page 12 of 12