Published in final edited form as:

J Pediatr Health Care. 2013 ; 27(6): 511–516. doi:10.1016/j.pedhc.2013.07.011.

Coverage of Palliative and Hospice Care for Pediatric Patients with a Life-Limiting Illness: A Policy Brief

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Keywords

pediatric palliative care; pediatric hospice care; concurrent care waivers; Medicaid; affordable care act; health care reform

In the United States, three-fourths of the 50,000 pediatric deaths annually occur in the acute care setting, most often in an ICU without comprehensive palliative or hospice care management (Centers for Disease Control and Prevention, 2012; Davies et al., 2008; Friebert, 2009; Himmelstein, Hilden, Boldt, & Weissman, 2004). In 2000, the American Academy of Pediatrics (AAP) issued a report recommending implementation of an integrated palliative care approach, beginning at the time of diagnosis, and focusing on the provision of curative therapies as well as comfort measures to increase the quality of life throughout the disease trajectory across settings (AAP, 2000). The 2003 Institute of Medicine (IOM) report *When Children Die* further found deficits in families ability to access comprehensive palliative care models and offered recommendations to include comprehensive palliative care models in both public and private insurance plans for reimbursement (Field & Behrman, 2003).

Palliative care is often initiated at the time of diagnosis for a life-limiting or life-threatening condition and is focused on symptom management, addressing psychosocial and spiritual needs, and goal-setting for the patient and family (Field & Behrman, 2003). Hospice services often incorporate the palliative care approach, but are usually limited to a specific time frame preceding the end-of-life. The issue of a comprehensive palliative care model forgoing curative therapies to pursue hospice care services has been a pervasive barrier to obtaining hospice and palliative care services for children. Because life-limiting conditions in children are commonly unpredictable, adult definitions of hospice care which include

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The authors declared no potential conflicts of interest and there was no financial support with respect to the research conducted.

specific prognostic factors and forgoing curative therapies to qualify offer substantial impediments for children to obtain services (Himelstein et al., 2004). Concurrent curative care in pediatrics allows for curative treatments to target the underlying disease (i.e. chemotherapy, dialysis, anti-rejection medications) while also remaining eligible to receive hospice care for physical (symptom-based), spiritual, psychosocial, and cultural considerations at the end of life (Lindley, 2011).

For children enrolled in Medicaid, pediatric palliative and hospice care has historically been covered through individual state waiver programs, but these programs vary widely state-to-state and present challenges in terms of the scope and coverage (Catalyst Center, 2011). Within the past decade, several states have offered mechanisms to support concurrent curative and hospice care coverage for pediatric patients who qualify (state exemplars found in the Table). These initiatives were important precursors to the provision in the 2010 Patient Protection and Affordable Care Act (ACA) which allows for concurrent curative and palliative care for pediatric patients who are enrolled in Medicaid or the Children's Health Insurance Program (CHIP) (H.R. 3590-111th Congress: Patient Protection and Affordable Care Act, 2010 section 2320).

The purpose of this policy brief is to examine the policy antecedents that allowed for inclusion of the concurrent coverage of palliative and hospice care waiver for Medicaid reimbursement in the ACA, and present strategies for the pediatric health care provider to advocate for full implementation of concurrent pediatric palliative care and hospice services in all states.

States Lead Access to Palliative and Hospice Care

The Home and Community-Based Services program under Section 1915c of the Social Security Act allowed states to offer benefits to enrollees to allow them to remain in their home community rather than to be hospitalized (Catalyst Center, 2011). These 'wrap services' included specialized home health care, case management, respite care and family support services, expanded income eligibility for Medicaid, and Medicaid and CHIP waivers that meet Federal requirements (Catalyst Center, 2011; "Medicaid/CHIP Waivers", 2012).

Florida became the first state to publically finance a program (PIC: TFK) to support concurrent palliative and curative care for the pediatric population through a Medicaid waiver in 2005 (Dabbs et al., 2007; Knapp et al., 2008). In 2009, California began a program based on the concept that care delivery could be performed using concurrent palliative and curative therapies in the home and community (Catalyst Center, 2011). California, urged by the California Department of Health Care Services, pushed forward legislation to help ensure long-term sustainability of the program through a pediatric palliative care waiver, and enacted The Nick Snow Act (Assembly Bill 1745), named after a young California patient with end-stage neuroblastoma. Nick Snow was a prolific supporter for hospice and palliative care after he received these services in his home and had substantial improvements in physical and emotional health (Dabbs et al., 2007). Illinois and Colorado implemented similar 1915c funding and reimbursement mechanisms. Other states such as New York and North Carolina have targeted the 1915c waiver in the context of medically fragile children. New York provides a *Care at Home* waiver serving children from birth through 17 years old who are determined to be physically disabled through the Social Security Income (SSI) criteria and would otherwise need to be placed in a skilled nursing facility (*Pediatric Concurrent Care*, 2012). North Carolina offers services through the *Community Alternatives Program for Children* including children under the age of 21 with a serious ongoing illness or chronic condition requiring prolonged hospitalizations.

The state of Washington decided that it's Pediatric Palliative Care benefit should be dually approached through both Medicaid programs and an interpretation of the federally mandated Early, Periodic, Screening, Diagnosis, and Treatment program (EPSDT), a program that requires states to screen and treat low-income children (Dabbs et al., 2007). The EPSDT was applied to the Medicaid Act of 1967 and is often considered the child health package of Medicaid provisions. The Washington Department of Social and Health Services Health Recovery Services Administration contracts with community hospice and home-care agencies as well as private payers which allows for most children in Washington who are in need of these services to be covered (Dabbs et al., 2007).

Independently State-Funded Programs

In 2006, Massachusetts signed a law providing for the creation and funding of the Pediatric Palliative Care Network (PPCN) as a part of the state Health Care Reform Act (Bona, Bates, & Wolfe, 2011). The Massachusetts Health Reform Law included a one-time \$800,000 appropriation for pediatric palliative care and 10 hospices received the initial funding for training, development and implementation (Dabbs et al., 2007). Unlike prior Medicaid waiver initiatives, this program is independently state-funded and is a community-based program providing services primarily in the home for children with wide ranges of life-limiting conditions, even when cure is a possibility (Bona et al., 2011; Catalyst Center, 2011). A key distinction of this program is that eligibility is not based on family income or entry into Medicaid (Catalyst Center, 2011). PPCN does not include provision of medications, durable medical equipment, personal care assistants, home health aides or financial assistance and a child must continue to receive these services through their primary health insurance or state-based Medicaid (Bona et al., 2011). Any costs for services not provided for through the state funding or reimbursed through private insurance or Medicaid become the responsibility of the hospice provider (Dabbs et al., 2007). A barrier to this type of programming is achieving continual financial support to keep the program sustainable when the initial monetary provision and funding period ends.

Implementation Challenges under Affordable Care Act

While several states offered concurrent curative care programs prior to health care reform, the federal mandate under in the ACA offers similar potentials for enrollment into hospice care for those seeking simultaneous curative and palliative treatment for children and their families who live in states that do not already have programs. The federal provision impacts children who are less than 21 years of age with a terminal illness who are eligible for the state's Medicaid or CHIP programs. The concurrent care waiver has the potential to have a significant positive impact on quality end-of-life care delivery for children with life-limiting illnesses. If implemented through state Medicaid agencies, Section 2302 of the ACA would eliminate provider challenges denying concurrent curative and palliative therapies for eligible children. Given that other states have already implemented concurrent curative therapy programs, implementation of the federal provision seems politically feasible. However, many challenges remain during this period of implementation of the ACA.

Physicians must still certify that the child is within the last six months of life

As previously described, this criteria is a really difficult target to assess for children with life-limiting conditions (Concurrent Care for Children Implementation Toolkit, 2011). Experts suggest that early initiation of palliative care is appropriate at the time of diagnosis to assist with the entire disease trajectory and has a greater impact the earlier it is initiated (Field & Behrman, 2003). This specification would delay enrollment until the anticipated final six months of life.

Children who are eligible are limited to the reimbursement services provided under Medicaid and/or CHIP

These services and offerings differ from state-to-state and are often constrained with budgetary issues. Individual states are able to provide expanded pediatric hospice care services beyond the scope of the specific concurrent care/Medicaid provision similar to programs outlined in Florida, California, Washington, and Massachusetts. However, 19 states have CHIP programs separate from Medicaid and these states do not provide a hospice benefit, so developing one will provide barriers to implementation (Lindley, 2011). Also, budget uncertainty in regards to Medicaid and CHIP hospice benefits remains a large and unsolved issue as current reauthorization for CHIP ends in 2013.

Provisions are still largely hospice-only and community-oriented

Challenges remain for providing comprehensive palliative care services earlier in the disease trajectory, and to be reimbursed in hospital-based programs. There is a great potential for fragmented care because the vast majority of curative care is still provided through hospitals and clinics with a variety of healthcare providers and specialists. Anticipated hospice provisions are largely focused in the home and other community settings (Lindley, 2011). Health care delivery remains uncoordinated at times and providers often rely on the families to manage the coordination during this already stressful time (Lindley, 2011). Finally, the provisions are largely focused on hospice and end-of-life and not on inclusion of general palliative care provisions.

The ACA provision does not provide concurrent care coverage requirements for children on private insurance or Medicare

A majority of terminally ill children are covered by private insurance with a very small number enrolled in Medicare (those who qualify often have end-stage renal disease and require dialysis) (Field & Behrman, 2003). While section 2302 of the ACA provides the foundation for the potential to improve access to palliative care services for those enrolled on Medicaid/CHIP, private insurers are not mandated to offer such provisions. Therefore, there is a potential for disparities in access to quality care end-of-life for those who are not eligible for hospice coverage while concurrently receiving curative therapy.

An intended outcome of the ACA was to significantly reduce the number of uninsured Americans through expansion of Medicaid and the state health insurance exchanges (Holahan, Buettgens, Carroll, & Dorn, 2012). Following the 2012 Supreme Court decision upholding the constitutionality of the ACA *individual mandate*, states now face a decision about whether or not to adopt Medicaid expansion (Holahan et al., 2012). The vast majority of the money required to facilitate individual states' expansion would be provided by newly allocated federal Medicaid dollars and would support the overall number of Medicaid enrollees (Holahan et al., 2012). Since some states are rejecting the Medicaid expansion under the ACA, there is the potential for significant impact on pediatric palliative and hospice care services and disparities in access for children and families across states.

Conclusion

The concurrent care provision in the ACA offers a great opportunity nationally for all children and families to obtain palliative care and hospice services. If access to palliative care services increases, more specialized providers are needed at the end-of-life. Pediatric nurse practitioners (PNPs) and pediatric health care providers specially trained in palliative and hospice care could decrease fragmentation of end of-life care, improve access to concurrent care services, and decrease public health cost burden of care for these children. PNPs and pediatric health care providers must advocate for the implementation of the

concurrent care provisions in the ACA, and understand the reimbursement mechanism for concurrent care services in their state in order to advocate for sustained coverage of these important services for children and families.

Acknowledgments

The authors have great appreciation for Journal of Pediatric Health Care's Health Policy editor Karen Duderstadt for her thoughtful editorial suggestions.

Authorship and publication of this article was financially supported while the lead author was a post-doctoral research fellow at Wake Forest University Cancer Prevention & Control Training Grant, Division of Social Sciences & Health Policy NIH *5R25CA122061-05*.

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Table

State-based Exemplars of Pediatric Palliative and Hospice Care Models

State	Name of Mechanism	Purpose	Eligibility
California	Partners for Children A 1915c Medicaid waiver which led to AB1745: The Nick Snow Children's Hospice and Palliative Care Act	To provide pediatric palliative care services to allow children, who have a California Children's Services (CCS)-eligible medical condition with a complex set of needs, and their families the benefits of hospice-like care in addition to state plan services during the course of an illness, even when the child does not have a life expectancy of six months or less. Based on the principle if curative treatment is provided along with palliative care, there can be an effective continuum of care throughout the course of the medical condition Offers: care coordination, art/music/play therapy, family training and education, respite care, support counseling, bereavement counseling	A child who: -Lives in a Waiver county -Enrolled in Medi-Cal (California's Medicaid program) and qualifies for CCS -Is eligible for full medical benefits -Is 20 years of age or younger -Has one of the following CCS eligible medical conditions: cancer, cystic fibrosis, brain or head injuries, spinal muscular atrophy, Duchenne's muscular dystrophy, ventilator dependent, heart defects or conditions, problems following a transplant, leukodystrophies gastrointestinal problems: dependent on parenteral nutrition, liver or small bowel transplant,
Colorado	Children w/Life Limiting Illness Waiver 1915c Medicaid waiver	To keep children with life-limiting illnesses out of the hospital and in the home as much as possible. Waiver removes barriers to a continuum of care by removing current state plan traditional hospice requirements that preclude the pursuit of curative treatments while providing palliative care. If curative treatments are provided along with palliative care, there can be an effective continuum of care throughout the life of the child. Offers: palliative/supportive care services, art/music/play therapy, respite care.	A child who: -Less than eighteen years of age -Is unmarried -Determined to have a developmental disability -Meet the immediate care facility for developmentally disabled criteria -Lives at home with their family when the waiver services are in place -Demonstrates a behavior or has a medical condition that requires intense direct human intervention at least once every two hours during the day and on a weekly average of once every three hours during the night.
Illinois	Pediatric Palliative Care Act. Legislation enacted in 2010, under 3 year pilot period	Community-based pediatric palliative care allows for children and families to receive pain and symptom management and psychosocial support in the comfort of home setting, thereby avoiding excess spending for emergency room visits and certain hospitals. Offers: a pediatric nurse for pain and symptom management, music/art/play therapy, family counseling, respite care and bereavement services	A child who: - Under 18 years of age -Is enrolled in the medical assistance program under Article V of the Illinois Public Aid Code and suffers from a potentially life-limiting medical condition -Has a life-limiting condition including: cancer, end-stage lung disease, severe neurological conditions, degenerative neuromuscular conditions, genetic syndromes, congenital or acquired heart disease, end-stage liver disease, end-stage kidney failure, metabolic disorders, congenital diseases of the gastrointestinal system, congenital skin disorders
Florida	Partners in Care: Together for Kids (PIC) Medicaid 1915b waiver	In response to the critical need to provide palliative care earlier in children's illnesses, Florida became the first state to develop and implement an innovative model of care that provides services from the point of diagnosis onward, thereby waiving the 6-month or less life expectancy requirement for reimbursement. Offers: pain and symptom management, patient and family counseling, music/art/play therapy, specialized nursing care, psychosocial and spiritual therapy, respite care, bereavement support	Patients and their families are eligible to receive services if: -The patient is under 21 years of age. -Has been diagnosed with a "life-limiting condition" with life expectancy less than 21 years of age. -The patient must reside in the State of Florida and be enrolled in his or her regional Children's Medical Services Network. The patient also must have Medicaid, Title XXI (Florida KidCare), or CMSN Safety Net funding. -The primary physician must refer the patient to the PIC program and certify a life-limiting condition. Annual renewal of this certification is mandated.
Massachusetts	Pediatric Palliative Care Network via The Massachusetts Health Reform Law of 2006	Health Reform Law included one-time allocation of \$800,000 to select 10 community hospices to provide integrated pediatric palliative care.	Residents of the state of Massachusetts: -Less than 19 years old -Diagnosis of life-limiting condition (no requirement of life expectancy)

State	Name of Mechanism	Purpose	Eligibility
Washington	Interpreted the federal Early Periodic Screening, Diagnosis, and Treatment program to include certain palliative care benefits	Offers: pain and symptom management, case management and assessment, social services, counseling and bereavement services, volunteer support, respite services and complementary therapies Model allows hospice agencies to provide intermittent care early in the trajectory and concurrent with the child's curative therapies Offers: six pediatric palliative care contacts per client per month, which may include: registered nurse, social worker, occupational therapy and physical therapy Services limited to patient bereavement care/psychosocial needs (not including family)	<i>A child who:</i> -Is eligible for Medicaid -Is under the age of 21 -Has a life-limiting medical condition with complex needs that requires case management and coordination of medical services