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Original Article

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Abstract

Context. In 2010, California launched Partners for Children (PFC), a pediatric palliative care pilot program offering hospice-like services for children eligible for full-scope Medicaid delivered concurrently with curative care, regardless of the child's life expectancy.

Objectives. We assessed the change from prior to PFC enrollment to the enrolled period in: (1) health care costs per enrollee per month (PEPM); (2) costs by service type and diagnosis category; and, (3) health care utilization (days of inpatient care and length of hospital stay).

Methods. A pre-post analysis compared enrollees' health care costs and utilization up to 24 months prior to enrollment with their costs during participation in the pilot, from January 2010 through December 2012. Analyses were conducted using paid Medicaid claims and program enrollment data.

Results. The average PEPM health care costs of program enrollees decreased by \$3,331 from prior to their participation in PFC to the enrolled period, driven by a reduction in inpatient costs of \$4,897 PEPM. PFC enrollees experienced a nearly 50% reduction in the average number of inpatient days per month, from 4.2 to 2.3. Average length of stay per hospitalization dropped from an average of 16.7 days prior to enrollment to 6.5 days while in the program.

Conclusion. Through the provision of home-based therapeutic services, 24/7 access to medical advice, and enhanced, personally tailored care coordination, PFC demonstrated an effective way to reduce costs for children with life-limiting conditions by moving from costly inpatient care to more coordinated and less expensive outpatient care. PFC's home-based care strategy is a cost-effective model for pediatric palliative care elsewhere.

Key Word: Palliative, pediatric, concurrent care, policy, cost **Running head**: Pediatric Palliative Care Policy Implications **Accepted for publication**: February 13, 2016.

Introduction

The estimated prevalence of children with life-threatening illnesses worldwide is hard to measure and estimates range from 10-16 to 32 per 10,000 (1, 2). In the U.S., this translates to as many as 500,000 children, of whom more than 40,000 die annually (3). Because life-threatening illnesses among children are much rarer than among adults, families often find themselves financially and emotionally unprepared to deal with the illness. Pediatric conditions are also different from the more prevalent terminal illnesses in adults and may require different modalities and plans of care, in particular more aggressive care up to the end of life (4). Length of illness varies widely in children because of differential development and resilience, and end-of-life care can extend over many years and through several developmental phases (4-6).

Children ages zero through 20 are susceptible to and diagnosed with age-specific medical conditions, and consequently have age-specific treatment goals and needs. According to the Institute of Medicine, pediatric palliative care seeks to relieve symptoms associated with a serious medical condition or its treatment, and to enhance the quality of life for children and their families by addressing their unique psychological, social, and spiritual needs (7). For the child, palliative care may include pain and symptom management to address disease and treatment side effects, and child life counseling and expressive therapies that provide the child with coping mechanisms and tools for self-expression. For the family, palliative care may include training on how to navigate the health care system, make the best treatment decisions, provide optimal care for their child, and bereavement counseling before and after the passing of a child.

Pediatric palliative care is also unique from the provider perspective. Caring for children with life-threatening illness may be more resource-intensive than for adults, and hospices, which traditionally provide adult palliative care, may not be prepared to care for a population with

different needs than their usual patient population (8, 9). Hospices that are willing to provide pediatric care may require additional training for their providers and need to undergo structural changes to provide that care.

Pediatric palliative care is a much newer phenomenon than adult palliative care. The American Academy of Pediatrics recommended in 2000 that pediatric palliative care begin upon the diagnosis of a child's life-threatening condition and continue for the duration of the disease, alongside curative care or life-saving treatment (10). In light of this recommendation, persistent rising health care costs, and the ensuing trend of moving more patient care out of hospitals and into the home, a critical need exists to find new models to deliver coordinated, patient- and family-centered, community-based, and cost-effective care for children with life-limiting conditions. Efforts to facilitate the delivery of pediatric palliative or hospice care may enable a larger percentage of terminally ill children to receive high-quality care in their own home (11, 12). As home health technologies develop, so does the range of services. A growing body of evidence suggests that the location in which children receive palliative care has significant implications. When palliative care is provided in the home, parental satisfaction appears to be high, and subsequent adaptation and outcomes for parents and siblings improves (12-15). One model for such care is Partners for Children (PFC), a pediatric palliative care program in California. This paper describes PFC, addresses the policy context for the development of the program, and presents an evaluation of the program's cost effect. The impact of PFC on the family experience has been described previously (16).

The Changing Policy Landscape of Pediatric Palliative Care

On a federal level, the Concurrent Care for Children Requirement (CCCR Section 2302) of the 2010 Patient Protection and Affordable Care Act (ACA) cemented in law concurrent

pediatric and curative care for ill children. This legislation spared families the difficult choice to forego all curative treatment before receiving hospice benefits. Despite this important development, the ACA did not change Medicaid's stipulation that children have no more than six months to live before being eligible for palliative care benefits.

The needs of children and families dealing with life-threatening and life-limiting illnesses have been increasingly recognized by states and Medicaid through cost-neutral waiver programs, including those in Florida (the first, in 2005), Colorado, and California. California passed the Nick Snow Children's Hospice and Palliative Care Act (AB 1745) in 2006. The law enabled the state to develop a pediatric palliative care pilot program offering hospice-like services for children eligible for full-scope Medicaid to be delivered concurrently with curative care, regardless of the child's life expectancy. The last feature was a departure from the federal Medicaid stipulation that pediatric hospice care only be covered during the last six months of life.

California's pediatric palliative care initiative was implemented through the CMS §1915(c) waiver option, which allows states to explore provision of long-term care services in home- and community-based settings. The CMS waiver encourages testing of innovative strategies to reduce the need for costly institution-based care and to increase quality of care and life through more extensive care coordination and therapeutic services. In line with these goals, California designed the Pediatric Palliative Care Waiver to improve the quality of life for children and their families through the provision of supportive home-based services, and to minimize hospital stays through the use of community-based care. A three-year pilot program, known as Partners for Children (PFC), was approved in 2008 and the first children were enrolled

in January 2010. Based partially on the program evaluation findings presented in this paper, the program was extended from the end of 2012 through 2017.

The program is a collaboration among California Children's Services (CCS, the state's Title V Maternal and Child Health Block Grant program for children and youth with special health care needs(17)) at the state and county levels, special care centers where children receive curative treatment, and local licensed private home health agencies, hospices or contracted agencies that voluntarily participated in the program.

Core Elements of Care

PFC provided the following palliative care services: 1) comprehensive care coordination; 2) expressive therapies, including art, music, play, and massage for the child; 3) family education, including instruction on providing care and operating medical equipment; 4) respite care in and out of the home to provide needed rest for the primary caregivers; 5) family and bereavement counseling; 6) pain and symptom management; and 7) 24/7 on-call nursing support services through participating hospice and home health agencies to provide advice on urgent care questions and further facilitate access to care by a healthcare professional familiar with the child's unique condition. Where applicable, these services were available to a "family unit," which varied by the individual case and could include parents, legal guardians, siblings, and/or significant others.

Eligibility and Enrollment

Children and their families either self-referred to PFC or were referred by a physician, another health care provider such as a hospice or home health agency, or a nurse liaison. To be enrolled in PFC, children and young adults had to be 20 years of age or younger, live in one of the 11 participating counties, and have full-scope, no share-of-cost Medicaid, and an eligible

condition. Eligible children also had to meet the necessary level of care, by which a physician had to declare on the referral form that a child was at- risk of having at least 30 inpatient days during the subsequent 12 months as a result of his/her qualifying condition if the child did not enroll in PFC. Nurse liaisons were responsible for authorizing all services at the county level and ensuring that waiver services met the needs of enrolled children and families and program requirements. In conjunction with the hospice/home health agency, nurse liaisons were responsible for monitoring hospice/home health care coordinators' comprehensive coordination of enrollees' care. The hospice/home care agency care coordinator coordinated all medical and community services for the child, accompanied the child and family to scheduled appointments, and generally facilitated communication between the family and service providers. In addition to 22 hours of initial assessment services, the program covered 4 to 12 hours of case management per month.

Methods

Data and Sample

Over the three-year pilot period, 151 children enrolled in PFC. The cost and utilization analyses were based on a subset of children (N=132) who were enrolled for at least 60 days, the minimum hypothesized amount of time needed for the program to have an effect on health care utilization. Cost analyses were conducted using data obtained from the California Department of Health Care Services (DHCS), including paid Medicaid claims and PFC enrollment data. *Study Design*

The goals of the program evaluation reported here were to assess the change from prior to enrollment to during the enrolled period in: 1) costs per enrollee per month; 2) costs by service type (inpatient, outpatient, emergency department, and pharmacy) and diagnosis category; and,

3) utilization (days of inpatient care). A pre-post enrollment analysis of individual enrollees' health care costs was conducted, comparing enrollees' health care costs up to 24 months prior to enrollment with their costs during participation in the pilot, from January 2010 through December 2012. A six-month run-out was applied to the claims data, such that any claim with a check (payment) date more than six months from the service end date was dropped. The run-out period was necessary due to the standard delay between service provision and claim payment in Medicaid. We also allowed an extra three months to account for the lag caused by Medicaid claims file production. The claims data for the final analyses were obtained in October 2013, accounting for the run-out and lag on claims up to December 2012, when the PFC pilot ended. The utilization analysis is based on claims data from enrolled individuals. Significance of the differences between pre- and post-enrollment costs and utilization was measured using paired t-tests, signed rank tests, and count models, to account for possible non-normal distribution of costs in the enrollee population. Total savings were calculated by multiplying the total member months of enrollees by the mean savings per enrollee per month (PEPM).

Results

Enrollees' Characteristics

Between January 2010 and December 2012, 151 children enrolled in the PFC pilot. Of those, 132 were enrolled in the program for at least 60 days and were included in the cost analyses. Demographic and descriptive characteristics of the 132 enrollees are presented in Table 1. No significant differences were found between the overall enrollee population and the population included in the cost analyses. Enrollees were more likely to be male (57%) and Latino (60%). The most frequent primary diagnosis was a neurologic condition (30%), followed by cancers (20%) and pulmonary and neuromuscular conditions (11% each).

Costs

Paid claims analysis demonstrated wide variations in cost among enrollees, ranging from \$0 to \$537,000 pre-enrollment and from \$0 to \$464,691 post-enrollment. Mean PEPM health care costs of children in PFC decreased significantly from \$15,643 prior to their participation in the program to \$12,312 while enrolled, a pre-post difference of \$3,331. Most of the savings were realized through a reduction in inpatient costs of \$4,897 PEPM, which was slightly modified by increases in outpatient and pharmacy services (Fig. 1). Enrollees on the higher end of the cost spectrum exhibited larger savings in the post-enrollment period than those on the lower end of the cost spectrum, with the median costs (not shown here) higher in the pre-enrollment period than post-enrollment, but with 75% already showing a significant reduction in cost.

Reductions in inpatient costs were consistent across nearly all of the disease categories studied. Seven of the eight categories saw the percentage of costs associated with inpatient stays decrease from pre- to post-enrollment, most notably among children with cardiac conditions (71% of costs in the pre-period vs. 31% in the post-period) (Fig. 2).

Extrapolated across the three program years, the savings of \$3,331 PEPM equated to \$5.2 million in 2010, \$10.5 million in 2011, and \$15.7 million in 2012, based on increasing enrollment in the program over the pilot period.

Utilization

PFC enrollees experienced a nearly 50% reduction in the average number of inpatient days per month, from 4.2 to 2.3 (Fig. 3), a significant difference. The reduction was driven by major changes in three diagnosis categories – cardiac, pulmonary, and transplant. The average number of hospitalizations was reduced during the program period, from 0.26 PEPM prior to enrollment to 0.20 PEPM during the program, although this difference was not significant.

Average length of stay per hospitalization dropped significantly from an average of 16.7 days prior to enrollment to 6.5 days while in the program. The 30-day readmission rate (hospital admission within 30 days of the previous discharge) was reduced from 45% of admissions to 37% of admissions, although this decrease was not statistically significant.

Discussion

Through the provision of home-based therapeutic services, 24/7 access to medical advice, and enhanced, personally tailored care coordination, the PFC model demonstrates an effective way to reduce costs for children with life-limiting conditions. The savings of \$3,331 PEPM was the result of the dramatic decrease in inpatient costs, operationalized through major reductions in the frequency and length of hospitalizations, and a relatively smaller increase in outpatient costs. This major shift – from costly inpatient care to more coordinated and less expensive outpatient care – is associated with PFC's home-based care model. It is notable that this shift occurred in a culturally diverse sample in which more than three-quarters of children were from ethnic minority populations. These results were consistent with preliminary results of this project suggesting a potential significant decrease in cost between the pre- and post-care periods.(18)

Along with cost reductions, our study demonstrated a statistically significant decrease in average length of stay in the hospital as well as a nearly 50% reduction the average number of inpatient days per month. A recently published systematic review on the effect of pediatric palliative care programs on health care resource utilization and costs among children with life-threatening conditions demonstrated heterogeneity in the quality of methodology across studies. The authors reported no conclusive findings due to conflicting results on cost of care and an overall trend of reduction in length of stay (19). The cost decrease we find in this study, therefore, is consistent with some studies(20-23) but inconsistent with others, including a more

comprehensive analysis that included costs of hospital and hospice care and showed an increase in the cost of care (24). Our finding of a reduction in length of stay is consistent with most other studies (19, 25).

The significance of care coordination in the structure and success of PFC should not be understated and may be the force behind some of the observed cost savings. This is especially plausible given that the cost savings notably occur mostly among the highest-cost children, who are likely to exhibit more complex needs and thus benefit most from the robust care coordination that was a key component of PFC. Each child and family was assigned a care coordinator (registered nurse or master of social work), a nurse liaison, and a multidisciplinary team of providers at the contracted care agency. In conjunction with the family, the care coordinator developed a Family-Centered Action Plan (F-CAP), a comprehensive care plan that highlighted each child's and family's needs and desires. F-CAPs were one of the waiver's main tools to limit the need for hospitalizations while improving quality of life and were to be completed within 14 days of enrollment. They allowed the care coordinator to manage most aspects of the child's care with the child's and family's self-reported needs in mind, relieving the family of many duties. F-CAPs were designed to be updated at least bimonthly to ensure accuracy of information, including demographics, medical diagnosis and condition, physical assessment, pain assessment, nutritional risk screening, family composition, spiritual/religious affiliations and cultural issues, and the risk/home environment. Additionally, all family members, including the child, were asked about their perceptions of the illness and health care goals. The F-CAP was translated to accommodate Spanish-speaking families. The concept of the individualized F-CAP counteracts a general lack of care coordination for CYSHCN and confirms the need for coordination targeted specifically at pediatric services (26-28). While coordinated efforts across multiple specialty

services are often necessary for CYSHCN and form the backbone of better care, PFC's focus on the entire family recognizes the broader social context in which children with life-limiting conditions may thrive. We, therefore, strongly believe that some of the elements of care that characterize this program have contributed to its success.

While the evaluation results are encouraging, it is important to note that the cost analyses are based on a pre-post comparison of individual enrollees health care costs and thus could not account for confounders such as environmental or historical factors, including other changes in policy, reimbursement, provider supply, or inflation, all of which could have contributed to changing costs over the period of the PFC pilot. A difference-in-differences approach, in which the enrolled children would have been compared over the same time period to a similar group of children who did not enroll in PFC, would have controlled for these outside factors by comparing the pre-post change in the enrolled group to the pre-post change in the control group. While this approach would have been preferable to the pre-post design, we were unable to identify an appropriate control group, despite having access to paid claims for CCS enrollees. The level of disease severity of PFC children prior to enrollment was substantially greater, on average, than any other group of children identifiable through the CCS program, even when limiting the potential control group to the top 1% of CCS children. While we did not have access to data to clinically assess the change in health status of the children, future research should assess the child's health condition throughout the pre-and post-enrollment periods.

Family-centered care coordination appears to be a promising tool to enhance care for children with potentially life-limiting health conditions. In expanding the reach of such strategies, it is important to assess the financial viability of providing services to children with life-limiting conditions for hospice and home health agencies in order to ensure a sufficient

supply of providers. Participating hospices and home health agencies incur additional costs beyond those typically associated with adult palliative care, such as provider training regarding the unique needs of children, billing, and other administrative expenses. Additional reimbursement to support administrative costs may be crucial to recruit and retain provider agencies. Given the early evidence of cost savings in PFC and feedback from participating providers that reimbursement rates were insufficient, DHCS approved an additional reimbursement of \$300 per enrollee per month at the end of the pilot period. Thorough analyses of the cost of service provision to hospices and home health agencies would be beneficial to potentially adjust reimbursement levels and reduce any undue financial strain on providers. Given the novelty of the family-centered, community-based pediatric palliative care model, the health care community must be educated and adequately reimbursed to ensure that children with life-limiting conditions are referred to the most appropriate available services.

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Services. AU: ANY CONFLICTS OF INTEREST?

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	n	%
Total	132	100
Age		
Less than 2	14	11
2 to 5	28	21
6 to 10	42	32
11 to 15	23	17
16 to 20	25	19
Gender		
Male	75	57
Female	57	43
Missing		
Race/Ethnicity		
Latino	79	60
White	11	8
Asian/Pacific Islander	6	5
Black	5	4
Other/Missing/Unknown	31	23
Primary diagnosis		Y
Neurologic	39	30
Cancer	27	20
Pulmonary	15	11
Neuromuscular	14	11
Cardiac	12	9
Transplant	11	8
Metabolic	6	5
Other*	8	6
Average length of enrollment (days)	361	

Exhibit 1: Demographic and Descriptive Characteristics of All Enrollees and Those Enrolled for at 60 Days, 2010-2012

Source: UCLA analysis of PFC enrollment data provided by DHCS.

*Other includes gastrointestinal conditions and enrollees whose primary diagnosis was "Other and unspecified postsurgical nonabsorption."

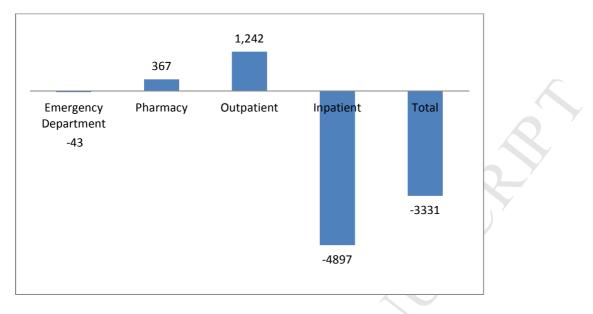


Exhibit 1: Pre-Post Change in Per Enrollee Per Month Cost, by Service Type, 2008-2012

Source: UCLA analysis of MIS/DSS claims, MEDS and CMS Net data.

Note: ED = emergency department; RX = pharmacy; OP = outpatient; IP = inpatient.

Note: Long-term care was examined as a separate service type but was too small to report separately and was included in the IP service category.

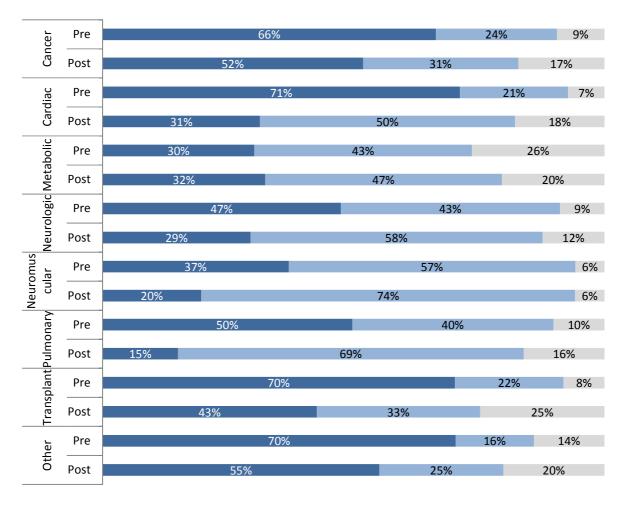


Exhibit 1: Cost Distribution by Type of Service and Diagnosis Category, 2008-2012

■ IP ■ OP ■ RX

Source: UCLA analysis of MIS/DSS claims, MEDS and CMS Net data.

Note: IP = inpatient; OP = outpatient; RX = pharmacy.

Note: ED percentages were not included due to small size.

Note: Other includes gastrointestinal conditions and enrollees whose primary diagnosis was "Other and unspecified postsurgical nonabsorption."

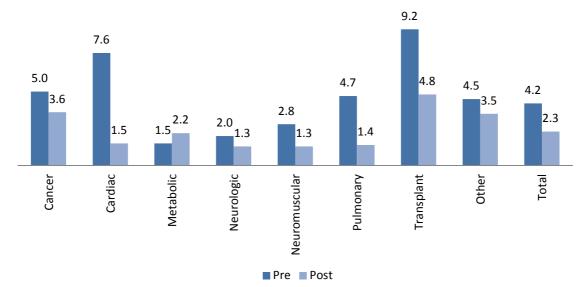


Exhibit 1: Mean Number of Inpatient Days PEPM, Pre- and Post-Enrollment, by Diagnosis Category, 2008-2012

Source: UCLA analysis of MIS/DSS claims, MEDS and CMS Net data.