

Impact of a Pediatric Palliative Care Program on the Caregiver Experience

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California's pediatric palliative care program Partners for Children uses family-centered care coordination to offer hospice-like therapeutic, respite, and pain management services for children delivered concurrently with curative care and regardless of the child's life expectancy. As an early implementer of concurrent care for children, the program provides evidence of the impact of concurrent care on children and their families. Program impact on caregivers' perceptions of their levels of stress and worry was measured using random effect growth curve models that included survey wave, caregivers' perceived family support, and the child's age and disease severity. All other data were descriptive and subject to univariate analysis. Worry and stress improved in the overall study population between the baseline and follow-up surveys. Family support was

predictive of reductions in stress and worry. Disease severity was predictive of stress. Family-centered care coordination is a promising tool to enhance care for children with life-threatening health conditions and reduce caregiver stress and worry. Program strategies, including individualized care planning, access to a 24/7 nurse line, and a focus on the entire family, can be a model for other states as the need for integration of pediatric palliative care for seriously ill children becomes a national public health priority.

KEY WORDS

caregiver experience, community based, concurrent care, palliative care, pediatric

Children aged 0 to 20 years have age-specific conditions and consequently have age-specific treatment goals and needs. From the time of diagnosis with a life-threatening disease and as a supplement to clinical treatment, pediatric palliative care provides children with holistic care that considers every aspect of the effect the diagnosis will have on the child's and family's physical, psychological, and spiritual health.¹ For the child, palliative care may include pain and symptom management and child life counseling and expressive therapies that provide the child with developmentally appropriate coping mechanisms and tools for self-expression. For the family, palliative care may include training on health care system navigation, treatment decisions, optimal care for their child, and bereavement counseling before and after the death of a child.² Pediatric conditions are different from more prevalent terminal illnesses in adults and require different modalities and care plans.³

In response to the need for comprehensive pediatric palliative care, in 2006 California developed a pilot program offering hospice-like therapeutic, respite, and pain management services for children eligible for full-scope Medicaid to be delivered concurrently with curative care and regardless of the child's life expectancy. California's pediatric palliative care initiative was implemented through a Centers for Medicare & Medicaid Services waiver that encourages testing of innovative strategies to reduce costly institution-based care and to increase quality of care and quality of life (QOL) through extensive care coordination

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and therapeutic services. In line with these goals, California designed the Pediatric Palliative Care Waiver to improve QOL for children and their families through supportive home-based services and to minimize hospital stays through community-based care.

A 3-year pilot program, known as Partners for Children (PFC), was approved in 2008. The first children were enrolled in January 2010. The PFC program is administered by the California Department of Health Care Services through California Children's Services Nurse Liaisons. Partners for Children contracts with nurses and social workers at hospice and home health agencies to serve as holistic care coordinators to help families manage their child's care based on each child's and family's identified needs. Partners for Children care coordinators complete a formal evaluation, the Family-Centered Action Plan, at least every 60 days to ensure that the family's needs and goals are at the forefront of decisions about the child's care. The Family-Centered Action Plans are reviewed by the referring physician. The care coordinator contacts the family at least monthly and often accompanies the caregiver on visits to physicians and/or to Individualized Education Plan conferences at the child's school. In addition to continued care coordination, children receive pain and symptom management and expressive therapies including art, music, play, and massage. Families receive education, including instruction on providing care and operating medical equipment, counseling and bereavement services, access to a 24/7 on-call hospice or home health agency nurse, and respite care in and out of the home to provide needed rest for primary caregivers.

The Affordable Care Act of 2010 has since enshrined in US federal law the ability of children with life-limiting conditions to receive palliative and curative care concurrently in the last 6 months of life.⁴ Prior to the Affordable Care Act's passage, most families had to make the painful decision to forego further potentially curative treatment in order to receive palliative care. Having the option to continue palliative care during treatment can alleviate the pain and adverse effects that a child may endure during continued treatment and reduces the dilemmas parents face when weighing treatment options.²

As an early implementer of concurrent care for children, California's experience with PFC provides insights into the potential of concurrent care. We undertook research to measure the program's impact on caregivers' levels of stress and worry. Based on literature reviews and expert consultation, we found that home-based care and shared decision making, both key aspects of PFC, lead to a greater sense of personal control, QOL, and satisfaction among caregivers.⁵⁻⁹ These existing data led us to hypothesize that family support systems may play an important role for caregivers dealing with a child's life-limiting illness. We also developed an innovative method to measure the severity of

the child's disease as a potential predictor of caregivers' stress and worry.

METHODS

To qualify for the program, children must be younger than 21 years, have full-scope Medicaid, reside in 1 of 11 participating California counties, and have a qualifying life-limiting condition.¹⁰ They must additionally meet the level-of-care determination, which requires that a physician assert that the child is likely to be hospitalized for at least 30 days in the coming year due to their eligible condition(s).

Survey Items

Generic health-related QOL instruments assess physical, emotional, and social constructs, but often miss less-generalizable domains such as pain, fatigue, depression, spirituality, social interaction, and desire for autonomy. Many studies have used the Pediatric Quality of Life Inventory Generic Core Scale in asthma, cancer, heart disease, rheumatology, and diabetes patients.¹¹⁻¹⁶ However, there are other pediatrics diagnoses in which standard QOL instruments such as the Pediatric Quality of Life Inventory Generic Core Scale have not been tested.¹⁷ Given the lack of a QOL tool suitable for this population and concern about length, we limited the survey to short single-item questions to prevent undue burden on families in already difficult circumstances. In consultation with experts who provide care to children and families dealing with life-limiting illnesses, we developed a set of questions about specific aspects and behaviors associated with stress and worry to assess the patient and family experience. Stress and worry were each measured by an aspect of the caregiver experience—stress by trouble sleeping and worry by feeling worried about the ability to manage their child's health. The questionnaire contained a single question on each aspect, with a 5-point scale ranging from "never" to "all the time." The categorical descriptors in the scale were associated with numerical values within the survey to make interpretation of the scale continuous. Caregivers' ratings of support received from spouses/partners, grandparents of the child, other family members, and family friends were combined to construct a family support variable that was included as an additional predictor of stress and worry (questionnaire items available in the Appendix). The questionnaire also measured caregivers' perceptions of PFC's ability to reduce or control the child's pain and other symptoms.

Survey Delivery

Caregivers were surveyed upon their child's enrollment in PFC and at 6-month intervals as long as their child remained enrolled. California Children's Services Nurse Liaisons conducted the surveys in the caregiver's home or by telephone. The analytic sample included all caregivers



who responded to at least 1 survey. Because of the small number of caregivers completing surveys beyond the second follow-up, the analysis was based on 3 survey waves (baseline and 2 follow-ups).

Analytical Methods

We constructed a variable indicating each child's disease severity to test our hypothesis that disease severity would be positively associated with stress, worry, or both. We based the variable on the severity stages defined by the Chronic Illness and Disability Payment System.¹⁸ This system uses health care claims to categorize beneficiaries in state Medicaid programs. We analyzed the PFC program's paid claims and encounter data to construct the Chronic Illness and Disability Payment System variable.

To investigate the change in caregivers' response over time, we used random effect growth curve models, which allowed us to control for within-caregiver correlation between multiple responses from the same participants.^{19,20} The model included the outcome variables stress and worry, a "survey wave" variable representative of the time of each survey, and covariates of caregivers' perceived family support and the child's age and disease severity. This model allowed us to measure the impact of these additional variables on changes in stress and worry beyond the effect of the time in the program. We considered the eligibility criteria of full-scope Medicaid to serve as an income control variable. We conducted additional analysis to compare caregivers with fewer than 3 surveys to those who completed surveys during all 3 waves to confirm that attrition was random and justify modeling the responses of the missing surveys for the 93 respondents who completed the first survey.

RESULTS

Between January 2010 and December 2012, 145 children enrolled in PFC. The primary caregiver of 107 of the children participated in at least 1 survey, an overall rate of 74%. Of the 107 surveys, 14 were excluded because of incomplete responses for some or all of the outcome variables, resulting in a sample of 93 and a response rate of 64% during the first survey wave. Subsequent waves resulted in substantial attrition to 50 responses during the second survey wave and 18 responses during the third survey wave. However, we confirmed via comparative analysis that the attrition was not related to the child's disease severity.

Demographic and descriptive characteristics of the 93 respondents and their children are presented in Table 1. Enrolled children ranged in age from 1 to 20 years, and the mean age was 9.6 years. The most prominent primary diagnosis was hypoxic-ischemic encephalopathy (31%). Primary caregivers tended to be Latino (69%) and married or living with a partner (53%).

When analyzed in the conditional growth curve model, worry and stress improved in the overall study population between baseline and follow-up surveys. The reductions over time were significant when controlling for the effects of family support and the child's age and disease severity, resulting in a 0.26-point reduction per survey wave for both worry and stress (Table 2; for worry, $P < .05$, 95% confidence interval [CI], -0.47 to -0.05 ; for stress, $P < .05$; 95% CI, -0.48 to -0.04).

Predicted mean changes in stress and worry over time are shown in the Figure. The qualitative descriptors associated with the stress and worry scales demonstrate that caregivers, on average, moved from feeling worried "most of the time" toward "sometimes" and crossed the threshold from feeling stress greater than "sometimes" to less than "sometimes" over the course of the 3-wave study period.

Family support was also predictive of reductions in both stress and worry. Every point increase on the 10-point scale used to rate family support (the higher the score, the greater the perceived family support) was associated with a 0.09-point decrease in the frequency of caregivers reporting stress ($P < .05$; 95% CI, -0.17 to -0.01). Each point increase in family support was associated with a 0.17-point decrease in caregivers' worry ($P < .05$; 95% CI, -0.28 to -0.06).

Disease severity was also significantly predictive of stress, with each unit increase in severity associated with a 0.01-point higher average frequency of stress ($P < .05$; 95% CI, 0.00-0.02). Age was not independently associated with changes in caregiver stress and worry.

Caregivers' perceptions of PFC's ability to reduce or control the child's pain and other symptoms received average ratings of 8.6 and 9.3, respectively, on a 10-point scale.

DISCUSSION

Partners for Children's success in reducing caregivers' stress and worry related to their child's care is an important achievement. It is also notable that this was a culturally diverse sample with 87% of children from ethnic minority populations. While reductions in the child's pain and other symptoms were subjectively measured, a primary caregiver's interpretation of a child's pain may be accurate, particularly in chronically ill children.^{21,22} Partners for Children's ability to reduce a child's pain in the eyes of the caregiver has major implications for the emotional well-being of the caregiver, who can be deeply affected by a family member's pain.²³ Partners for Children services such as tailored care coordination and a 24/7 nurse line are designed to help families manage their child's condition in a noninstitutionalized setting to improve cost and QOL outcomes. Given the pervasive and varied effects a child's illness can have on caregivers,²⁴ it is critical that such services enhance a family's confidence and reduce



TABLE 1 Demographic and Descriptive Characteristics of PFC Children and Their Primary Caregivers (n = 93)

	n	%
Total	93	100
Characteristics of children		
Age, y		
1-5	24	26
6-12	38	41
13-20	31	33
Gender		
Male	54	58
Female	39	42
Race/ethnicity		
Latino	64	69
White	13	14
Black	4	4
Asian/Pacific Islander	1	1
Multiple	4	4
Other	6	6
Missing	1	2
Primary diagnosis		
Hypoxic-ischemic encephalopathy	28	31
Chronic respiratory failure	11	12
Transplant-related complications	11	12
Malignant neoplasm	9	10
Spinal muscular atrophy	5	5
Cerebral degenerations usually manifest in childhood	4	4
Hereditary progressive muscular dystrophy	4	4
Leukemia	3	3
Other	18	19
Characteristics of caregivers		
Marital status		

Continued

TABLE 1 Demographic and Descriptive Characteristics of PFC Children and Their Primary Caregivers (n = 93), Continued

	n	%
Married/living with partner	49	53
Never married/separated/divorced/widowed	28	30
Missing	16	17
No. of children aged <18 y in household		
1	19	20
2	24	26
3	21	23
4+	13	14
Missing	16	17

Abbreviation: PFC, Partners for Children.

stress and worry in order to make such improvements possible. The use of qualitative descriptors related to the point scale used in the survey provides a clearer picture of the improvement.

Our finding that perceived family support is associated with reductions in caregiver stress and worry reinforces previous literature on children with special health care needs (CSHCNs). While the children enrolled in PFC are arguably different from the overall CSHCN population given the severity of their illnesses, the literature on CSHCNs is informative in understanding caretaking in this specific subset of CSHCNs for whom scant literature exists. Satisfaction with social support and the number of different available support have been independently linked to stress in mothers of CSHCNs.^{25,26} Social support has also been associated with a reduced sense of need for information among families of CSHCNs and a greater sense of family functioning.²⁷ Previous findings that the long-term stress of caring for a CSHCN can affect the mother's health suggest that there are also important physiological implications in caretaking.²⁸ The transitive effects of caregiver stress levels, including on their own health, should be considered in future evaluations of palliative care programs.

The significance of care coordination in the structure and success of PFC should not be understated. The concept of the individualized care plan counteracts a general lack of care coordination for CSHCNs and confirms the need for coordination targeted specifically at pediatric services.^{29,30} While coordinated efforts across multiple specialty services are often necessary for CSHCNs and form the backbone of



TABLE 2 Growth Curve Analysis of Change in Caregiver Stress and Worry (n = 93)

	Stress (95% Confidence Interval)	Worry (95% Confidence Interval)
Survey wave ^a	-0.26 ^b (-0.48 to -0.04)	-0.26 ^b (-0.47 to -0.05)
Disease severity	0.01 ^b (0.00 to 0.02)	0.01 (-0.01 to 0.02)
Age	0.02 (-0.01 to 0.05)	0.01 (-0.03 to 0.05)
Family support	-0.09 ^b (-0.17 to -0.01)	-0.17 ^b (-0.28 to -0.06)

^aSurvey wave is the change in time from baseline to first follow-up to second follow-up surveys.
^bSignificant at a level of P < .05.

better care, PFC's focus on the entire family recognizes the broader social context in which children with life-limiting conditions may thrive. The success of enhanced family-provider contact, achieved through consistent care coordination and regular updates to the Family-Centered Action Plan, confirms previous findings that effective communication improves QOL for families in pediatric palliative care programs.³¹

Disease severity appears to play a limited role in the caregiver experience, especially as it pertains to caregiver stress as operationalized through trouble sleeping. One of PFC's most important innovations is its availability to children with a wide range of disease progression, a change from more traditional palliative programs initiated only in the last 6 months of life. Our results showing that PFC may be more effective for children with less severe disease suggest that children and families would be best served by early referrals that allow PFC's intensive care coordination and child and family support programs to take effect and reduce stress before the child's disease has reached an advanced stage. Partners for Children's ability to help families of children with more severe illness nonetheless appears important. Despite the difficult situation of dealing with a child's illness, levels of stress and worry in caregivers of severely ill children trended downward across the study period when one might expect them to rise under the circumstances.

The study has several limitations. The questions measuring the patient and caregiver experience (available in the Appendix) have not been validated, and the limited size of the PFC population made it impossible to conduct factor analysis to measure validity within the present research. There are a number of validated instruments for measuring caregiver stress,²⁴⁻²⁶ but none dealt with the exact set of experiential variables we set out to measure. As such, we do not have an appropriate control group against which to measure the PFC population on these concepts. However, PFC services such as enhanced family-provider communication and coordination of social and community supports have been independently shown to improve the family experience. By using multiple innovative strategies in combination, PFC represents an improvement over

the current standard of care. Ninety-three caregivers represent a small sample size. While the changes in stress and worry were significant, a larger sample size would have allowed for additional testing of other factors, such as the effect of specific health conditions. A larger sample size would also have allowed us to conduct reliable factor analysis on our survey instrument, a limitation given that it has not been previously validated. The data were also unbalanced because of nonresponse by caregivers at different survey points, but we confirmed that the missing values were missing at random in order to justify the use of random-effect models. The 64% response rate is also a potential limitation, although previous research on children with public insurance and CSHCNs has obtained similar and often lower rates.³²⁻³⁴ The severity of disease in our study population means these caregivers may be under even more stress and time constraints than other parents of CSHCNs. Nonetheless, these findings provide evidence that home-based pediatric palliative care services support children receiving the services as well as their caregivers.

Given that families of PFC enrollees are dealing with their child's life-limiting condition, one would expect to see deterioration in QOL over time, particularly as their child's condition deteriorates, as previous research has shown.³⁵ The fact that caregivers report feeling less stress and worry is a strong indication of the success of the program. Family-centered care coordination appears to be a promising tool to enhance care for children with potentially life-threatening health conditions. Efforts

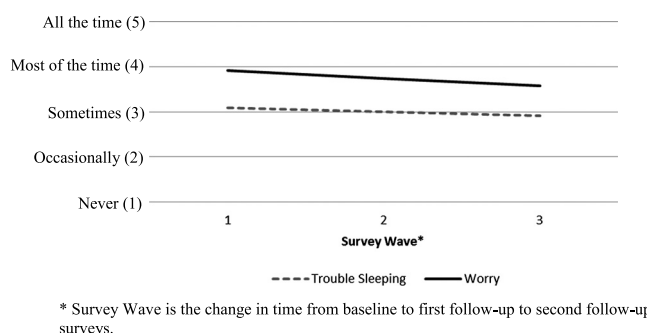


FIGURE. Predicted mean change in caregiver stress and worry.



should be made to educate the medical community regarding the relatively new practice of family-centered community-based pediatric palliative care. The study can serve as a model for other states as the need for integration of palliative care for seriously ill children becomes a national public health priority.

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APPENDIX. QUESTIONNAIRE ITEMS

CAREGIVER STRESS AND WORRY

Sometimes parents may feel stress related to the care of their child. They may feel that they have a hard time falling asleep or staying asleep. How often would you say you feel this way?

Never	Occasionally	Sometimes	Most of the Time	All the Time	Refuse	Don't Know
1	2	3	4	5	98	99

Sometimes parents may feel worried about managing their child's health. They may have a hard time keeping their mind on other things they are supposed to be doing such as work, household chores, or paying bills. How often would you say you feel worried related to managing you child's health?

Never	Occasionally	Sometimes	Most of the Time	All the Time	Refuse	Don't Know
1	2	3	4	5	98	99

FAMILY SUPPORT

Using any number from 0 to 10, where 0 is the worst possible and 10 is the best possible, what number would you use to rate the support you received from the following during the past 3 months?

Type of Support	Rate Support (0-10)
18.a. Spouse/partner	
18.b. Grandparents of child	
18.c. Other family members	
18.d. Family friends	

PERCEPTION OF CHILD'S PAIN AND OTHER SYMPTOMS

Using any number from 0 to 10, where 0 is the lowest amount possible and 10 is the highest amount possible, what number would you use to answer these 2 questions?

- (1) How much did the waiver services help you reduce or control your child's pain?
- (2) How much did the waiver services help you manage your child's other symptoms that come from being sick?