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### Title

Impact of a Pediatric Palliative Care Program on the Caregiver Experience

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## **Abstract**

**Purpose/Aims:** California's pediatric palliative care program Partners for Children employs 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.

**Design/Methods:** Program impact on caregivers' perceptions of their levels of stress and worry 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.

**Results:** 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.

**Conclusions:** 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**

Pediatric; Palliative care; Community-based; Caregiver experience; Concurrent care

## **Introduction**

Children ages zero through 20 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.<sup>1</sup> 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.<sup>2</sup> Pediatric conditions are different from more prevalent terminal illnesses in adults and require different modalities and care plans.<sup>3</sup>

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 and 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 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 three-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 (DHCS) through California Children's Services Nurse Liaisons (CCSNLs). PFC 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. PFC care coordinators complete a formal evaluation, the Family-Centered Action Plan (F-CAP), 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. F-CAPs 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 (ACA) of 2010 has since enshrined in U.S. federal law the ability of children with life-limiting conditions to receive palliative and curative care concurrently in the last six months of life.<sup>4</sup> Prior to the ACA'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 side effects that a child may endure during continued treatment and reduces the dilemmas parents face when weighing treatment options.<sup>2</sup>

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, quality of life, and satisfaction among caregivers.<sup>5-9</sup> 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 under 21 years of age, have full-scope Medicaid, reside in one of 11 participating California counties, and have a qualifying life-limiting condition.<sup>10</sup> 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 quality of life (HRQOL) instruments assess physical, emotional, and social constructs, but often miss less-generalizable domains like pain, fatigue, depression, spirituality, social interaction, and desire for autonomy. Many studies have used the Pediatric Quality of Life Inventory Generic Core Scale (PedsQL) in asthma, cancer, heart disease, rheumatology, and diabetes patients.<sup>11-16</sup> However, there are other pediatric diagnoses in which standard QOL instruments such as PedsQL have not been tested.<sup>17</sup> 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 five-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 Appendix A). 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 six-month intervals as long as their child remained enrolled. CCSNLs conducted the surveys in the caregiver’s home or by telephone. The analytic sample included all caregivers who responded to at least one survey. Due to the small number of caregivers completing surveys beyond the second follow-up, the analysis was based on three survey waves (baseline and two 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 (CDPS).<sup>18</sup> 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 CDPS 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. 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 three surveys to those who completed surveys during all three 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 one 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%).

**Insert Table 1 here (table at end of document)**

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,  $p < 0.05$ , 95% CI = (-0.47, -0.05); for stress,  $p < 0.05$ , 95% CI = (-0.48, -0.04)).

**Insert Table 2 here (table at end of document)**

Predicted mean changes in stress and worry over time are shown in Figure 1. 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 three-wave study period.

**Insert Figure 1 here (figure at end of document)**

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 ( $p < 0.05$ , 95% CI (-0.17, -0.01)). Each point increase in family support was associated with a 0.17-point decrease in caregivers' worry ( $p < 0.05$ , 95% CI (-0.28, -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 ( $p < 0.05$ , 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**

PFC'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. PFC's ability to reduce a child's pain in the eyes of the caregiver has major implications for the emotional wellbeing of the caregiver, who can be deeply affected by a family member's pain.<sup>23</sup> PFC services such as tailored care coordination and a 24/7 nurse line are designed to help families manage their child's condition in a non-institutionalized setting to improve cost and quality-of-life outcomes. Given the pervasive and varied effects a child's illness can have on caregivers,<sup>24</sup> it is critical that such services enhance a family's confidence and reduce 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 (CSHCN). While the children enrolled in PFC are arguably different from the overall CSHCN population given the severity of their illnesses, the literature on CSHCN is informative in understanding caretaking in this specific subset of CSHCN for whom scant literature exists. Satisfaction with social support and the number of different available supports have been independently linked to stress in mothers of CSHCN. Social support has also been associated with a reduced sense of need for information among families of CSHCN and a greater sense of family functioning.<sup>27</sup> 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.<sup>28</sup> 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 CSHCN and confirms the need for coordination targeted specifically at pediatric services. While coordinated efforts across multiple specialty services are often necessary for CSHCN 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. 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 quality of life for families in pediatric palliative care programs.<sup>31</sup> 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 six 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. PFC's ability to help families of children with more severe illness nonetheless appear 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 Appendix A) 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.

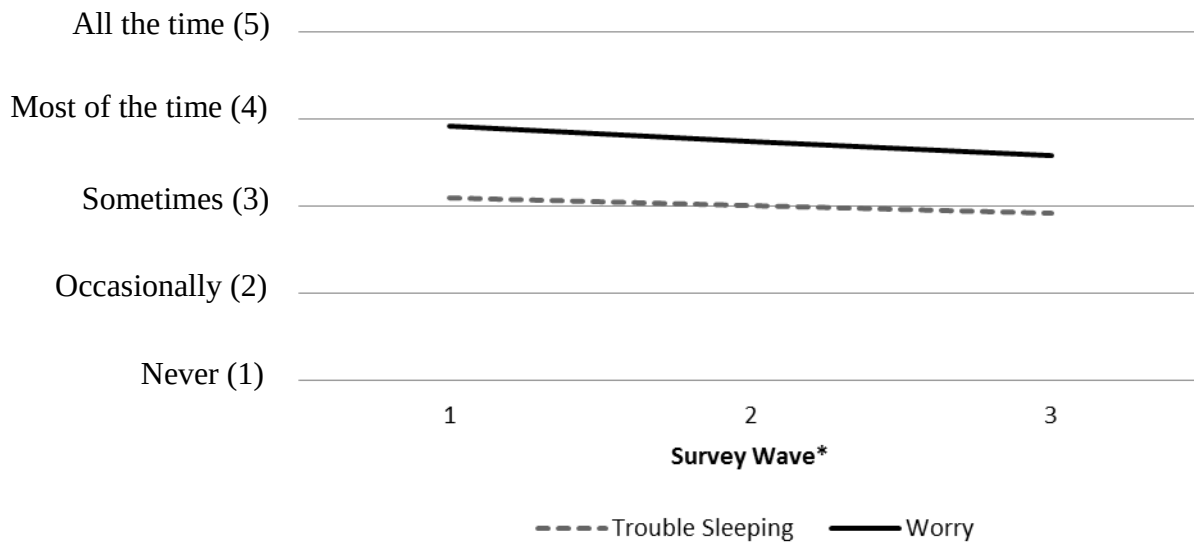
There are a number of validated instruments for measuring caregiver stress,<sup>24-26</sup> but none dealt with the exact set of experiential variables we set out to measure. As such, we do not have an appropriate control group against which to measure the PFC population on these concepts.

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 due to 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 CSHCN has obtained similar and often lower rates.<sup>32-34</sup> The severity of disease in our study population means these caregivers may be under even more stress and time constraints than other parents of CSHCN. 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 quality of life over time, particularly as their child's condition deteriorates, as previous research has shown.<sup>35</sup> 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 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.

### **Figure 1. Predicted Mean Change in Caregiver Stress and Worry**



\* Survey Wave is the change in time from baseline to first follow-up to second follow-up surveys.

## References