

Small mercies: Program for children with life-threatening conditions shows early success

August 30 2012, by Letisia Marquez

(Medical Xpress)—A child is desperately ill, and a family faces a stark choice: Should they try to save the child's life with therapeutic treatments, or ease the pain through hospice and other pain-relief services?

This is the current dilemma of families seeking support through Medicaid to care for a child with a life-threatening illness. Under current law, Medicaid recipients are only granted full access to both therapeutic and palliative services in the last six months of a child's life.

Seeking a better solution, California in 2009 launched a three-year [pilot program](#), ultimately covering 11 counties, that allows families to access in-home, coordinated, family-centered pediatric [palliative care services](#) alongside curative care, regardless of the child's [life expectancy](#).

As state lawmakers currently consider extending or expanding that initiative, known as the Partners for Children (PFC) program, the UCLA Center for [Health Policy Research](#) has released a new policy brief looking at the program's impact on children's quality of life, their parents' ability to cope with an enormously stressful situation, and the overall costs of caring for this high-treatment population.

Examining preliminary data, as well as the results of a survey with a select group of affected families, center researcher Daphna Gans and her co-authors found that, on average, the PFC program saved \$1,677 per child per month—an 11 percent decrease in spending. [Survey data](#) also

indicate that participation in the PFC program improved quality of life for the child and the family, the authors said.

"There seems to be early evidence that giving families in one of life's most [stressful situations](#) a wider range of choices is not only the right thing to do but the cost-effective thing to do also," Gans said.

Why? The authors found that the PFC program was successful in reducing the average number of days a child spent in the hospital by 32 percent through the provision of less-costly, supportive community and home-based services, such as in-home pain and symptom management, a 24/7 nurse line, family education, respite, expressive therapies and [family](#) counseling.

Specifically, the study found that before participation in the program, the majority of medical expenditures (65 percent) occurred in the costly in-patient hospital setting, with only 26 percent in out-patient settings, such as doctors' offices or clinics. After enrollment, only about half of expenditures (47 percent) occurred in hospital in-patient settings, with a larger share—39 percent—in community settings.

A survey of 33 families participating in the program showed a decrease in the reported frequency of sleeping difficulties, feeling nervous or tense, and feeling worried. Families also reported an increase in the frequency of feeling confident in their ability to care for the child.

"The data suggest that either/or is not the solution," Gans said. "Families need a broad range of choices to care for a very sick child at home, and they need it long before the child's condition becomes terminal."

Currently, the number of children nationwide living with a life-threatening condition and receiving treatment in community settings annually is estimated at half a million.

In California, as of March 2012, there have been 123 participants in the PFC program, ranging in age from less than 1 year old to 21.

Currently, policymakers are considering the advisability of extending the program beyond the 11 counties that now participate.

"We are encouraged both by these preliminary findings about the program's success and by the support we have heard from policymakers and others about the importance of sustaining and expanding this critical program," said Devon Dabbs, executive director of the Children's Hospice and Palliative Care Coalition, which funded the research. "We hope that other very sick children and their families in California will soon have the broader options offered to those already participating in the PFC program."

More information: Read the policy brief: "[Better Outcomes, Lower Costs: Palliative Care Program Reduces Stress, Costs of Care for Children With Life-Threatening Conditions.](#)"

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