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# Pediatric Palliative Care Research Network SHARE Study

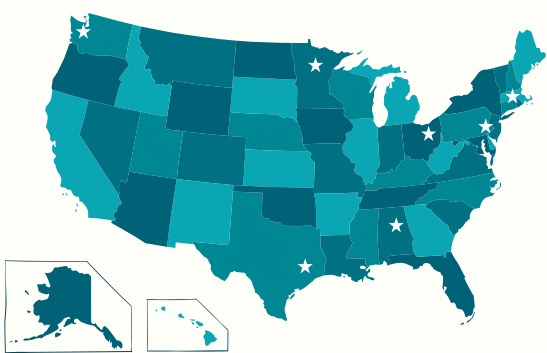
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Children's symptoms, parents' wellbeing, goals of care, and use of health care services: what do we know and why should it matter?



Little scientific data currently exist on symptoms of children receiving pediatric palliative care (PPC), the wellbeing of their parent caregivers, the goals of care for these children, and the use and cost of health care services among these children. Even less is known about how all of these things may change over time. And yet, **having this knowledge matters** because there may be patterns to how these things change over time, which could guide PPC treatment and decision-making for individual children and inform PPC policy at the national level.

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## 7 U.S. children's hospitals participated in this study:

- The Children's Hospital of Philadelphia
- Boston Children's/Dana-Farber Cancer Institute
- Seattle Children's
- Children's Hospital and Clinics of Minnesota
- Akron Children's Hospital
- Children's of Alabama
- Texas Children's

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### 1 Key Data

Collect data on patient symptoms, parent wellbeing, and other aspects of care directly from children and parents

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### 2 Explore Patterns

See how child symptoms and parent wellbeing change and relate to each other over time



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While this study is still ongoing, so far we have published two papers on what we have learned, with more to come.

Let's take a look at what we have learned so far...

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# "Polysymptomatology" in pediatric palliative care patients based on parents' reports

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Children receiving palliative care often have symptoms that are distressing to them and to their family caregivers. We don't know, though, how severe these symptoms are, how frequently they occur, how often symptoms occur at the same time (or "*polysymptomatology*"), and if symptoms vary across different diseases and children's ages.



This study included parents of children with different serious illnesses receiving pediatric palliative care across the 7 participating children's hospitals.



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## THE SYMPTOMS REPORTED MOST OFTEN INCLUDED:

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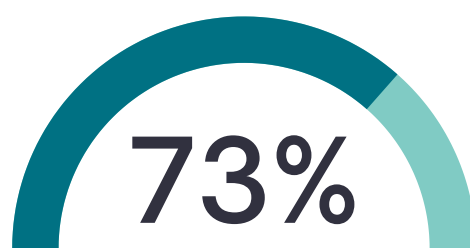
Pain	63.7%
Lack of energy	58.9%
Irritability	55.9%
Drowsiness	49.3%
Shortness of breath	46.3%

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AVERAGE SYMPTOMS PER CHILD:

**6.7**

OUT OF 20 POSSIBLE SYMPTOMS



of children had 5 or more symptoms **at the same time.**

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This study gives us important information about the symptoms experienced by children who are receiving pediatric palliative care, and reminds us of the importance of assessing and treating symptoms for all children, no matter the child's disease or age.

To view the full article, free of charge, please click here:  
<https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2782718?resultClick=3>

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# Pediatric palliative care parents' distress, financial difficulty, and child symptoms

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We know from previous research studies and in our work with families of children receiving pediatric palliative care that parents often suffer a great deal emotionally; yet, we did not know what aspect of children's illness impacts parents' mental health the most.

In this study, parents of children receiving pediatric palliative care participated. We looked to see how much a child's symptom burden and the family's financial difficulty impacted parents' level of emotional distress.



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Parents of children receiving pediatric palliative care were more likely to experience distress if...



...their family was having **more financial difficulty**

...their child was **experiencing more symptoms, at greater intensity**



Family financial difficulty, however, was more strongly associated with parents' level of distress than children's symptoms.

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These findings are important because helping families with financial challenges and improving children's symptoms may lower parents' distress and improve the wellbeing of parents of seriously ill children.

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# More information coming soon...

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...How parents' goals  
of care for their  
children change over  
time

...Relationship between  
child symptoms and  
parent wellbeing over time



For more information, please visit:

<https://www.research.chop.edu/feudtner-laboratory>

