

TRENDS in Pediatric Palliative Care Research (TPPCR) 2026; Issue #05: Commentary on

Pigani, F. et al.

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Abstract:

This TPPCR commentary discusses the 2026 paper by Pigani, F. et al., The impact of sleep disorders of children with severe medical complexity on their caregivers' sleep: A perspective from two pediatric palliative care centers., in the Italian Journal of Pediatrics.

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Sleep disruption is prevalent among children with medical complexity (CMC) but is often addressed with a primary focus on the child.¹ In practice, it is a family-level experience—one that affects caregivers who provide around-the-clock care and monitoring in the home. Despite this, data directly linking child sleep patterns to caregiver sleep outcomes remain limited. Pigani et al. help address this gap by examining these dyadic relationships in a pediatric palliative care population.²

In this descriptive study conducted at two palliative care programs in Italy, 15 CMC (median age: 10 years old) and their caregivers (N=26) were evaluated using a structured sleep questionnaire and a seven-day sleep diary. Most children (73%) had significant functional impairments, 73% required gastrostomy feeding, and 13% had a tracheostomy. Nearly half of children (47%) received regular sleep medications, while an additional 13% used sleep medications as needed, most commonly melatonin.

Children had a reported median nighttime sleep duration of 8 hours. Nearly 87% of children experienced nighttime awakenings, with a median of 2 awakenings per night. These interruptions were often related to care needs—such as suctioning, pain management, or nocturnal feeding—though in 22% of cases, no clear cause was identified.

Caregivers reported a median of 6 hours of sleep per night and estimated that they lost approximately 2 hours of sleep compared to what they felt they needed. On a 5-point scale, the impact of nighttime caregiving on sleep was rated as high (median 4).

The total amount of sleep children experienced was not associated with caregiver sleep loss (correlation = -0.28, $p = 0.404$). In contrast, the number of nighttime awakenings was

significantly associated with caregiver sleep loss (correlation = 0.72, $p = 0.012$). The overall level of medical complexity was not associated with these sleep patterns.

These exploratory data suggest that sleep disruption in families of children with CMC may be driven less by sleep quantity and more by the repeated demands of nighttime care. Even when a child appears to be getting enough total sleep, the night can still be defined by repeated awakenings and the need to monitor and respond quickly to changes in a child's condition. For many families—and for those of us who care for them—these findings will feel familiar.

I practice as a complex care pediatrician at the Children's Hospital Colorado Special Care Clinic, where we provide primary care for more than 6,000 CMC, and sleep is one of the most important and frequent issues I discuss with families. Sleep hygiene is always part of the conversation, but it is often not sufficient. Pharmacotherapy is commonly needed, and in this study more than half of children were using sleep medications.³ What this study helps clarify is why that approach alone is often not enough. While medications may improve sleep onset or duration, they rarely reduce the need for nighttime caregiving. In practice, that often means thinking beyond medications—to questions of who is awake overnight, what monitoring is truly necessary, and where additional supports might make a meaningful difference.

These findings also bring into focus an area of growing tension in clinical care: access to home nursing and overnight support. Increasingly, families are asked to meet very high thresholds by private and public insurance programs in the United States—often approaching ICU-level needs—to qualify for nursing services.⁴ Yet for many CMC, even without ventilator dependence or active titration of therapies, unpredictable nighttime interruptions are associated with measurable caregiver sleep loss. This is the scenario that often requires medical justification to

explain why a child who appears “stable” still requires overnight support. Data like these help make that burden visible. In this context, limiting access to overnight support—and contributing to chronic sleep disruption—undermines caregiver well-being, a central component of what makes care at home sustainable and safe.

As clinicians advocate for home-based supports, there is a need for stronger evidence to guide these decisions. Larger studies that incorporate objective sleep measures, alongside caregiver perspectives, would help quantify the true magnitude of nighttime disruptions and better identify where targeted supports could have the greatest impact.

References

1. Feinstein, J. A., et al. (2020). "Identifying Important Clinical Symptoms in Children With Severe Neurological Impairment Using Parent-Reported Outcomes of Symptoms." *JAMA Pediatr* 174(11): 1114–1117.
2. Pigani, F., Burlo, F., Peri, F., Bolognani, M., Uez, F., Barbi, E., & De Zen, L. (2026). The impact of sleep disorders of children with severe medical complexity on their caregivers' sleep: A perspective from two pediatric palliative care centers. *Italian Journal of Pediatrics*.
3. Blackmer, A. B. and J. A. Feinstein (2016). "Management of Sleep Disorders in Children With Neurodevelopmental Disorders: A Review." *Pharmacotherapy* 36(1): 84–98.
4. Foster CC, Turchi RM; Section on Home Care; Committee on Child Health Financing. Financing of Pediatric Home Health Care: Policy Statement. *Pediatrics*. 2025 Dec 1;156(6):e2025073624. doi: 10.1542/peds.2025-073624. PMID: 41242516.