Trends in Pediatric Palliative Care Research (TPPCR) 2021; Issue #11: Commentary on *Johnson et al.*

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Abstract:

This TPPCR commentary discusses the 2021 paper by Johnson et al, “Changing Pediatric Hospice and Palliative Care Through Medicaid Partnerships.” published in Pediatrics.

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Pssst! Have you heard? Hospice is no longer a dirty word. At least in pediatrics in the United States, that is. Johnson, et. al's article in *Pediatrics*, "Changing Pediatric Hospice and Palliative Care Through Medicaid Partnerships" delves into why and how.

In 2010, the United States passed the Affordable Care Act (ACA), an expansive piece of legislation that significantly altered the US healthcare system by increasing health insurance coverage and access to care.¹ As part of this reform, patients up to age 21 who are beneficiaries of Medicaid or Children's Health Insurance Program (CHIP), the publicly funded programs that provide health coverage to low-income patients,² may enroll in hospice care while also continuing to receive cure-directed therapies. This is in stark contrast to patients over age 21, who are eligible for hospice care only when they elect to focus on comfort rather than continuing cure-directed therapies.³ In other words, under the ACA, terminally ill children can benefit from the best of both worlds. This is termed concurrent care.⁴

Unfortunately, this change has not opened the door to all-encompassing care for seriously ill children in the US as was intended. As this article states, "more than a third of state Medicaid offices have not provided any guidance for providers" on how to implement this model of care. As a result, the law's application has varied from state to state. It is striking to realize that this variation translates into children in the majority of US states having no or limited access to the benefits of concurrent care. One of the states highlighted here, Georgia, has made impressive progress toward implementing concurrent care. Along the way, however, they have uncovered two major concerns within the state that I suspect persist throughout the country. First, hospices are often uncertain how best to care for pediatric patients - and from personal experience, I would add that many have staff who feel unprepared or unwilling to participate in this care. Second, the hospice providers who do care for pediatric patients often have difficulty making concurrent care a reality. Why is it so difficult? The answer to this brings us back to the fact that there exists no guidance; there is no set of instructions, regulations, or limitations from which to build a structure of providing and financing this care.

If you're reading this commentary, the answer to the question I posed at the start may be that yes, you do know that hospice services are available to terminally ill children in the US up to the age of 21 in

¹ Grace AM, Horn I, Hall R, Cheng TL. Children, Families, and Disparities: Pediatric Provisions in the Affordable Care Act. *Pediatr Clin North Am*. 2015 Oct;62(5):1297-311.

² Sommers BD, Grabowski DC. What Is Medicaid? More Than Meets the Eye. *JAMA*. 2017 Aug 22;318(8):695-696.

³ Centers for Medicare & Medicaid Services. (2021, December 1). *Hospice*. <https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/Hospice>

⁴ Lindley LC. Health Care Reform and Concurrent Curative Care for Terminally Ill Children: A Policy Analysis. *J Hosp Palliat Nurs*. 2011 Mar;13(2):81-88.

conjunction with, rather than instead of, cure-directed therapies. In addition to providing clear, step-by-step outlines of the ways in which three groups (Louisiana/Mississippi, Georgia, and Illinois) harnessed the expertise of a variety of stakeholders to not only successfully implement, but propel forward, the provision of current care to children within their borders, my hope is that it will also broaden awareness of this provision throughout the pediatric community. Although concurrent care for children became a possibility in the US eleven years ago, many pediatric providers remain unaware of this opportunity to extend hospice care to children as an addition to, instead of as a substitution for, their disease-directed care.

Broadening awareness of the availability of this care is necessary to increase access to it for terminally ill children in all states. As the article points out, the states who have succeeded in implementing such care have utilized the experiences and perspectives not just of hospice providers but of all also of pediatric subspecialists who deliver disease-directed treatment. All pediatric providers, no matter their area of focus, will inevitably care for a child who will die. However, many are unaware of just how early and wide-ranging this support for children and families can be. Educating our colleagues, especially those in specialties in which childhood death is unfortunately not a rarity, that hospice care can be provided as an adjunct to the rest of a patient's care, is a step forward. I chose to highlight this article because it not only provides first steps for all states to embark on optimizing care for seriously ill children. It also takes that first step for all of us, by increasing the awareness of pediatric providers that this option exists at all.