

Emerging Policy Opportunities: Advance Care Planning and Pediatric Palliative Care

Speakers:

- Brian W. Lindberg, Senior Public Policy Advisor, C-TAC
- Jessica Hausauer, PhD, Executive Director, National Coalition for Hospice and Palliative Care
- Arul Thangavel, MD, Chief Executive Officer, WiserCare
- Conrad Williams MD, FAAP, FAAHPM, Director, Palliative Care Program, MUSC Health System, Associate Professor, Department of Pediatrics, Medical University of South Carolina





Pediatric Palliative and Hospice Care Policy and Advocacy

October 21st, 2024

C-TAC Leadership Summit

Jessica Hausauer, PhD
Executive Director,
National Coalition for Hospice and Palliative Care

National Coalition for Hospice & Palliative Care (NCHPC)

Mission & Vision

We improve the care of people with serious illnesses by:

- Convening the field
- Advocating for equitable policies and improved health outcomes
- Establishing best practices & sharing resources

All patients, families and caregivers will have equitable access to quality palliative care and hospice care.

Our Members

14 national organizations representing the interdisciplinary field of palliative care and hospice care



Our Members



National Alliance
for Care at Home

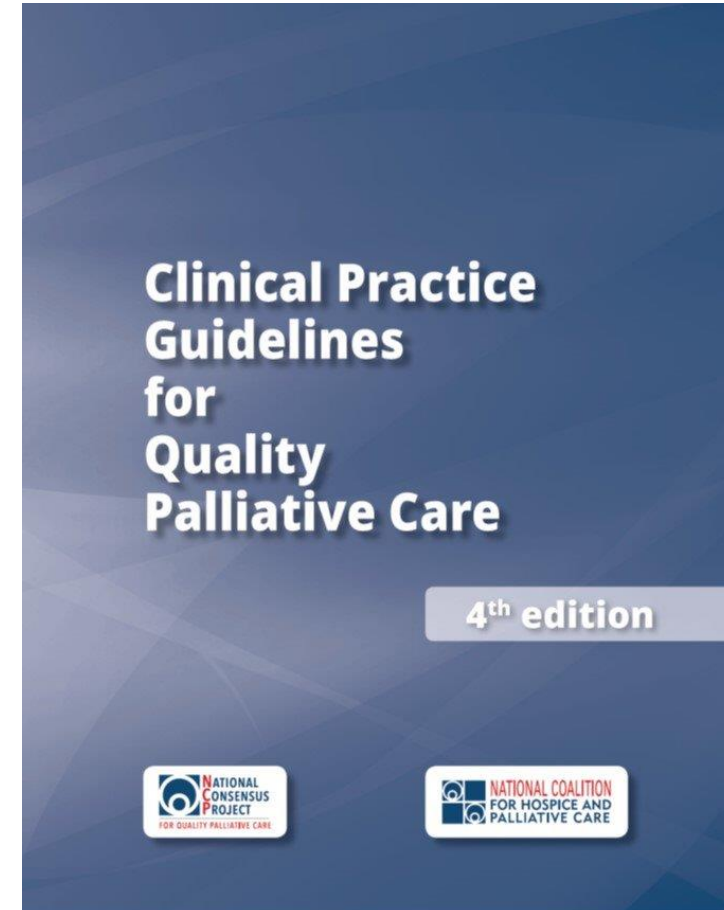


SOCIETY of
PAIN & PALLIATIVE CARE PHARMACISTS



Clinical Practice Guidelines for Quality Palliative Care, 4th edition

- For all people with serious illness, regardless of setting, diagnosis, prognosis, or age



Pediatric Division

- Started as a task force in 2020 after a convening of PPC leaders by the Center to Advance Palliative Care (CAPC)
- Established to elevate the pediatric palliative care perspective in national dialogues and decisions that impact the field
- Became a Division of NCHPC in 2023



Key Trends in Pediatric Palliative and Hospice Care

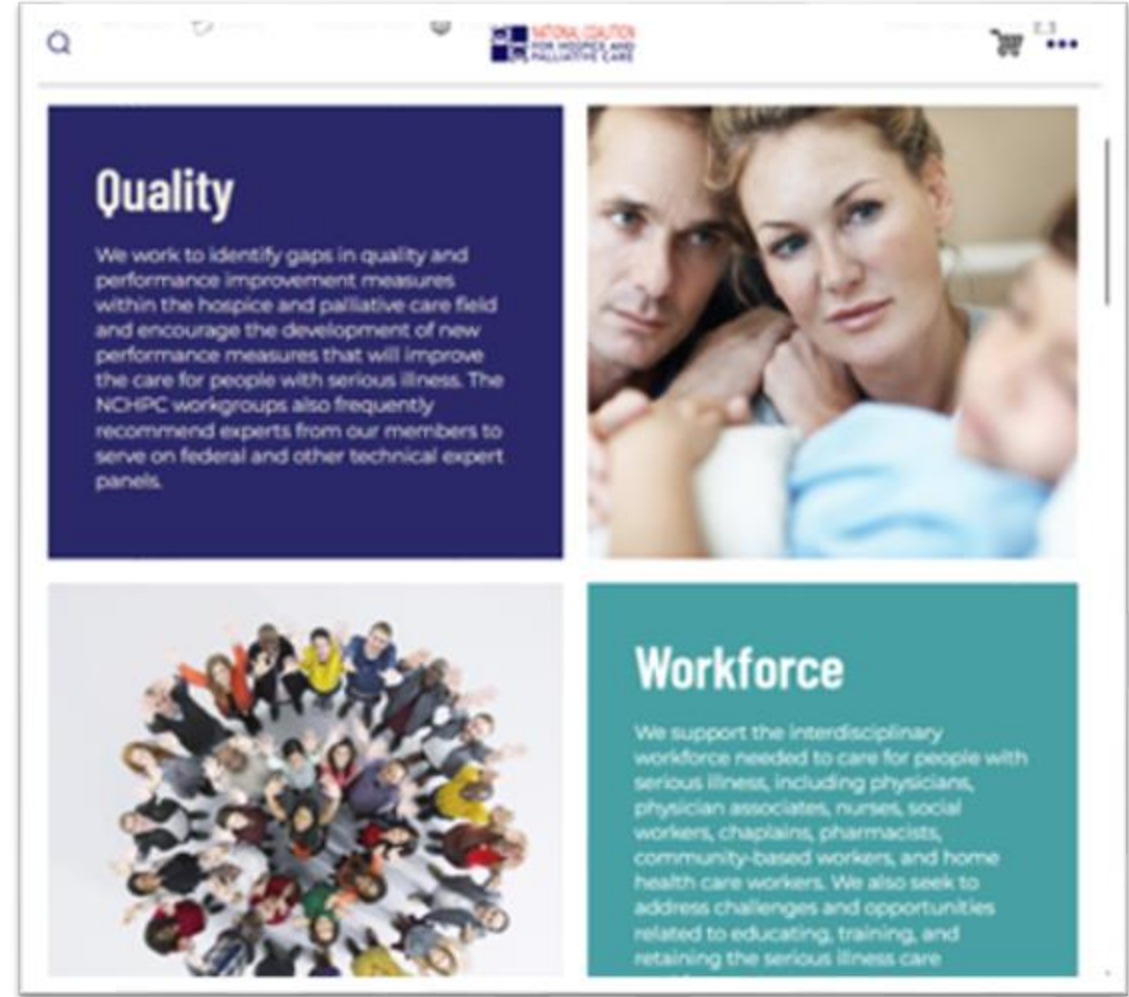
- Patient population is small compared to other groups but growing in number, diversity of need, and complexity (NHPCO 2023)
- Access is greatest in children's hospitals, variable in community-based settings, and challenging in rural areas (Weaver et al 2022; Kiefer Autrey et al 2023)
- Emerging concern is reduced access particularly in community-based hospice settings (anecdotal and preliminary research findings)
- Payer sources are mixed with Medicaid and CHIP most common (NHPCO 2023)
- Wide variations in access and policy implementation from state to state (Laird et al 2020)
- Pediatric specialist workforce shortages, maldistribution, and burnout (NASEM 2024)

Critical Barriers to Access

Workforce

Awareness

Payment



Current and Emerging Policy Priorities

- Palliative Care Hospice Education and Training Act
- Palliative Care Research Across the Lifespan Research Infrastructure and Funding
- Concurrent Care and Hospice Eligibility

North Star

“We don’t simply need another specialist to go to. We need someone to help us shoulder the heavy decisions, complex issues, and goals we face. We need help with dealing with ongoing pain and symptom management and working with specialists who get so used to seeing our child’s symptoms that they act like it’s not important, or that it’s normal for them to be in pain. We need someone to help us bring awareness of what quality of life is and how it impacts medical decisions. Families may not know how to advocate for PPC, but if they knew what they were missing, they would be strong advocates.”

- Jennifer Bartz, family advocate

Pediatric Division Members

- Holly Davis, MSN (NHPCO) – CHAIR
- Melissa Hunt, Pharm. D., BCPPS (SPPCP) – CHAIR ELECT
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- Maggie Rogers, MPH (ACS)
- Jim Santucci, CPA (Family Advocate)
- Tressia Shaw, MD (NAHC)
- Dannell Shu, MWS (Family Advocate)
- Amanda Thompson, Ph.D (APA)
- Christy Torkildson, Ph.D (HPNA)
- Emmalee Tresnan, CCLS (ACLP)
- Conrad Williams, MD (PCQC)
- Jillian Williams (Family Advocate)