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Claudia Delgado-Corcoran · Ryann Bierer · Lauren Cramer Finnerty · Katie Gradick · Brandy Harman · Mark Harousseau · Brooke Johnston · Sydney Kronaizl · Dominic Moore · Benjamin Moresco · Betsy Ostrander · Paige Patterson · Holly Spraker-Perlman · Amanda L. Thompson · Antonia Vitela-Elliott

Specialized Pediatric Palliative Care

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Foreword

Simply put, pediatric palliative care is increasingly recognized as an essential element in the comprehensive set of services and support that are necessary to care for children who are dealing with serious illness in a compassionate manner. The authors of this monograph provide us with a broad overview of the many details that define the "what" and "how" of state-of-the-art pediatric palliative care as we now understand it. Perhaps more importantly, these valued colleagues also give us a window into the "why" of pediatric palliative care, which we could describe as being our collective way to alleviate the suffering that the pediatric patient and their family experience as they navigate through an illness and care plan. The centrality of the connection between the work pediatric palliative care professionals do and the motivation that seems to routinely animate them is captured by the word "compassion." Drs. Trzeciak and Massarelli, in their now classic book entitled *Compassionomics: The Revolutionary Scientific Evidence That Caring Makes a Difference*, define compassion as "the emotional response to another's pain or suffering, involving an authentic desire to help" (2019, p. 5). One could make the case that it is exactly this "authentic desire to help" that defines the field of pediatric palliative care. Dr. Brené Brown's description of compassion characterizes well the pediatric palliative care occurring in our midst: "the daily practice of recognizing and accepting our shared humanity so that we treat ourselves and others with loving-kindness, and we take action in the face of suffering" (2021, p. 118). On an almost daily basis, those of us in pediatric health care actually witness the "authentic desire to help" combined with "action in the face of suffering" among our palliative care colleagues. Seeing their work in action assists those of us who are less skilled with how best to alleviate suffering and remain hopeful with the child and family with whom we are engaged in care.

As the authors of this monograph make clear, pediatric palliative care is a dynamic emerging sub-specialty within the broader area of pediatrics, and it is consummately an interdisciplinary effort that involves a number of professionals from a variety of other related fields. The definition of palliative care offered by the World Health Organization (WHO) (2020) best captures its comprehensive nature:

> Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment, and treatment of pain and other problems, whether physical, psychosocial, or spiritual. Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers.

Each of these interdependent team members makes a unique and essential contribution to understanding the needs of a given child and their family and helps craft a care plan that optimizes what health care has to offer.

In addition to discussing the concepts of the palliative care approach referred to the WHO's definition, the authors point out a number of challenges confronting their emerging field of practice. There is well-documented variability in access to pediatric palliative care services, both nationally and internationally, with more availability present in the United States at academic settings, most notably in the nation's children's hospitals and health systems. Not uncommonly, palliative care is not well understood by the lay public nor by providers in the healthcare field and is still confused with hospice care. While palliative care can include hospice services delivered to patients near end of life, it is much broader and not limited to end-of-life care.

Additionally, the authors provide us with information about specific populations of children that are likely to be served by pediatric palliative care teams, including those children seen in oncology, cardiology, and neurology as well as those with a variety of chronic and/or disabling conditions. The authors also offer valuable insights into the venues of care, spanning inpatient, outpatient, and home care settings. The data on the growth of pediatric palliative care teams is encouraging, but the obvious mismatch between the need for pediatric palliative care and the number of pediatric palliative care sub-specialists available to serve is striking. The authors issue a realistic call to action to close the gap between those who need pediatric palliative care and the number of skilled professionals necessary to provide that care in the coming decades. This call to action revolves around broader recognition of the importance of education and training in pediatric palliative care, continued prioritization of research and evaluation in order to expand the evidence base for such care, and increased attention to ongoing sustainable funding to support the delivery of this care to all children and families in need.

Reading through the material in this monograph, the essential nature of pediatric palliative care in the alleviation of suffering among seriously affected children and their families is clear. The connection between palliative care and the authentic desire to help is palpable and defines compassion. Whether in the field of pediatric palliative care itself or as one among the many who benefit from the work of pediatric palliative care providers, our collective responsibility remains to encourage and support those who courageously come forward to serve in this compassionate manner. The ensuing pages make the imperative clear: pediatric palliative care is the

healthcare system's way of showing children and their families that we care about helping them as they navigate through the many twists and turns along their healthcare journey. Let's all commit to doing our part to help alleviate suffering by advocating for and taking steps toward greater pediatric palliative care capability and availability in our healthcare settings for all children and families who may be in need.

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