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PEDIATRIC PALLIATIVE CARE (KS HOEHN, SECTION EDITOR)

Hot Topics in Pediatric Palliative Care: a Calm Island in Troubling Waters

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Abstract

In our world today, we are faced with disasters and shortages on a daily basis. In this article, we highlight some of the ways that pediatric palliative care practitioners can ease the burden and meet the needs of families in crisis.

Keywords Opioid shortage · Palliative care · Ethics · Natural disasters · Integrative medicine

The recent events of natural disasters and the ongoing opioid shortage in the USA have revealed how limited resources are in our world. In this edition, we highlight several current events and their impact on pediatric palliative care patients and providers [1–5]. We hope that scarcity breeds innovation; this is a crucial time in our history to address other ways of treating pain. Dr. Brown and her colleagues have provided us with a fresh tool kit of integrative methods to augment our pain management and minimize narcotic usage [1]. Imagine if all the hospitals had acupuncture available 5 days a week a first-line treatment for chronic pain? Imagine if we did guided imagery before every IV placement; the potential for growth of integrative medicine over time is incredible. These are just some examples of how palliative medicine specialists can improve the quality of care for all patients. Palliative medicine specialists employ a wide range of modalities with a focus on creative family-centered problem-solving. These techniques are critical to addressing the whole patient: mind, body, and spirit.

All critically and chronically ill children should have the involvement of a pediatric palliative care team; however, there is variability in when pediatricians refer to palliative medicine [6]. In the ideal world, palliative medicine would be integrated with curative medicine at the time of a life-limiting diagnosis; however, there may not be sufficient amounts of pediatric palliative medicine subspecialists available. Lupu et al. describe the acute shortage of hospice and palliative medicine physicians, growing to a deficit of 10,000 physicians, which will continue to grow over time given the paucity of fellowship programs in hospice and palliative medicine [7]. What should we do when everyone who would benefit from palliative care physicians cannot see one? Ensure that all pediatric subspecialists who are caring for critically ill and terminally ill children are versed in key components of symptom management and end-of-life care [2]. In this month's edition, the article by Rhee et al. discusses the unique skill set that pediatric palliative care providers have, yet framed in the reality that there are not enough board-certified pediatric hospice and palliative medicine doctors to see all the patients who would benefit from their services [2]. Similar to the military where people are trained to fill a variety of tasks depending on the need, pediatricians and pediatric subspecialty providers need to be trained in the basic tenets of family-centered pediatric palliative care. Blinderman and Billings wrote an extensive review on the key components of comfort care for actively dying patients in the hospital [8]. This includes specific guidelines for questions to be asked, since clear and compassionate communication is essential when discussing end-of-life care [9].

One of the challenges to providing this education is that the American Board of Pediatrics requires frightfully little palliative medicine education for any of the pediatric subspecialties (abg.org/content specifications.) The lack of specific content requirements on pediatric palliative care required in those training in high-acuity fellowships (PICU, NICU, Oncology, and ED) minimizes the importance of this training. With so many demands on trainees with work-hour restrictions and

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balancing clinical and educational requirements, fellowship training programs rely on the content specifications to prioritize their educational goals. For the care of all children and families, we need the American Board of Pediatrics to require in-depth palliative medicine and bereavement education for all residents and fellows. One idea would be for seminal articles to be required reading, for example the Pediatric Palliative Care review by Himelstein et al. should be a required read and handy reference for all physicians, those who care for dying children, and those who care for terminally ill adults who have young children. His table on perception of death by developmental stage is invaluable and provides specific suggestions on effective communication across stages [9]. This communication skill set is integral to building trusting relationships with families.

Without trust, we struggle to treat our patients and families. Families need trust in their health care team to ensure that all options have been explored for their child before accepting that death may be the outcome. Frader et al. take us on a journey over the ocean with the Charlie Gard case [3]. The family was reluctant to accept a prognosis of death if there were other, even theoretical options offered in the USA. The Charlie Gard case has lessons for everyone who treats rare diseases. Do we know live in a society where every treatment option, theoretical or not, needs to be offered before parents can accept death? How many treatments have to be tried and fail, despite a lack of evidence, before we are willing to call a disease terminal? How do we handle the distrust at the bedside international cases like these may cause? Their article highlights important points around what does it mean to do everything [3].

Doing everything in palliative care includes aggressive symptom management, and some symptoms are more distressing for families than others. Seizures can be very difficult for families to watch. Drs. Buhrfiend and Heydemann provide an exhaustive overview of some of the most challenging and refractory types of epilepsy that exist [4]. Their article describes novel treatments, including some only available in Europe. We are evolving into an international community where families travel across oceans and continents to explore every real or potential therapeutic options for their children. Sadly, only those families with abundant financial and other resources are truly able to avail themselves of all international options. Literature on health care disparities suggests that the opioid shortage will adversely impact those who identify as racial and ethnic minorities, as they already face limited access to pain specialists and analgesics [10, 11]. The massive shortage may exacerbate discrimination against patients who are already in pain. Palliative medicine specialists need to be at the table with hospital administrators, advocating how to adequately address patients' pain needs in the midst of shortages, while ensuring those in severe pain and those who are terminally ill do not feel abandoned. Palliative care specialists are integral to this dilemma, as their experience with multimodal analgesia can assist in designing opioid-sparing protocols, such as expanding the use of adjuvants like low-dose methadone, lidocaine [12], or ketamine [13] for sickle cell and complex pain. This epidemic of inadequate supply of opioids seems to be raging out of control, like a wildfire, but we have the expertise to help the health care system adapt to new scarcities.

What was the cause of these shortages? Was this opioid shortage precipitated by natural disasters? [14]. Some media outlets have highlighted key hospital items, such as IV bags, which are made in Puerto Rico and are now on shortage along with medications. These natural disasters have impacted families personally and hospitals nationally. Dr. Kang et al. describe how pediatric palliative care families were the most vulnerable victims of Hurricane Harvey [5]. This hurricane caused an estimated $190 billion worth of damage, but what we did not know until now was how tragically this impacted those already living through their worst nightmare, the loss of a child [15]. Pediatric palliative care patients are the most vulnerable patients in society, and their needs and their families' needs should be addressed when people are planning for natural disasters.

Perhaps when all is said and done, 2018 will be a game changer in novel and creative ways to treat pain. We will not let it be the year of extraordinary pain and suffering since we have an inadequate supply to meet the need. In the turbulent tide that is our world today, let us embrace and champion palliative care education for all trainees so that everyone has the skill set to be the calm island in the middle of a turbulent storm.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflicts of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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