



Pediatric palliative care specialists can support colleagues during pandemic

by Alexis Morvant M.D., M.A., FAAP; Lisa M. Humphrey M.D., FAAHPM, FAAP

Editor's note: For the latest news about the COVID-19 pandemic, visit <https://www.aapublications.org/news/2020/01/28/coronavirus>.

The COVID-19 pandemic is saturated with uncertainty, fear and volatile change. Pediatricians around the world are faced with understanding and explaining a complex natural disaster to children and their families while supporting them emotionally.

Pediatric palliative care (PPC) subspecialists are experts in mitigating suffering for children living with serious illness and are adept at emotionally guiding families through uncertainties. Moreover, PPC training teaches resiliency, self-compassion and communication skills to navigate the unknown. In this pandemic, PPC subspecialists can utilize these skills to support families and health care colleagues by teaching resiliency, modeling self-compassion and sharing PPC communication tools.

Establishing a new normal within erratic change and uncertainty will be challenging for patients, families and pediatricians alike, and all can benefit from resiliency training. Resiliency is the capacity to recover mentally and emotionally after a stressful experience. Abby R. Rosenberg, M.S., M.A., M.D., director of the Palliative Care and Resilience Lab at Seattle Children's Research Institute, proposes optimizing resiliency by mindful deep breathing, setting small goals, reframing thinking and practicing gratitude.

PPC practitioners support patient and caregiver reframing when a child's health status declines and new goals are necessitated. Reframing also is a powerful tool for pediatricians, especially to facilitate self-compassion. Gentle redirection to diminish self-judgment can contribute to improved overall well-being. Instead of thinking, "I should not be scared because others have it worse," perhaps suggest the mind to reframe, "I am scared, and that's OK because I'm human and it is a pandemic."

Such reframing requires awareness of one's emotions, another tool PPC subspecialists often utilize when working with families facing uncertainty. Differing and numerous emotions can be overwhelming. One way to take control is to name the emotion, such as hopelessness or anger, and then attend to it. Guilt is a pervasive emotion for clinicians, who may think: "I am not doing enough." Brené Brown, Ph.D., L.M.S.W., who researches shame and vulnerability, encourages health professionals to reframe inadequacy by remembering that when they are doing their best, they are enough.

PPC subspecialists often work with families struggling to define what a good parent is when cure is not possible for their child. Modeling the aforementioned behaviors can be educational for parents struggling to redefine the good parent role amid this pandemic. Additionally, specific PPC communications skills can assist parents in this reframing exercise. PPC encourages exploration of experiences and perceptions using the nonjudgmental, inviting phrase "tell me more" followed by silence. "Tell me more" indicates that you are keen to listen and learn. Silence creates space for patients and families to share their experiences, thoughts and feelings - to tell their stories. This tool may be helpful as pediatricians communicate with families who are scared, grieving the loss of normalcy or experiencing anticipatory grief.

Anticipatory grief is a dynamic process of experiencing impending feelings of grief when there is potential for loss. Interestingly, death is not a prerequisite for grief. David Kessler, an expert on grief and loss, explains that the collective experiences of discomfort during this pandemic and its associated uncertainty are grief. PPC subspecialists are experts in navigating grief with patients and can help their pediatric colleagues navigate grief



THE OFFICIAL NEWSMAGAZINE OF THE AMERICAN ACADEMY OF PEDIATRICS

AAP News

during the COVID-19 pandemic. Pediatricians can reach out to PPC subspecialists for resources and support.

Finally, COVID-19 is a shared experience among patients, their families and clinicians. They all fear what the future may hold and experience distress regarding the well-being of self and others, leading to countertransference and real empathy. For many clinicians, it is the first time a patient or family may say, "I'm scared," and they can respond with empathic authenticity, "Me too. Please tell me more..." The result is a vulnerable, authentic human connection.

Dr. Morvant is a member of the AAP Section on Hospice and Palliative Medicine, and Dr. Humphrey is a member of the section's executive committee.