

Living with COVID-19

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Issue Topic: Living with COVID-19

Welcome to the 62nd issue of our Pediatric e-Journal. It is important to note here that this issue was planned many months ago, but we still could not have imagined the world in which we find ourselves now with the coronavirus pandemic. Although older adults have suffered the brunt of the infection, the challenges this pandemic has created affect all of us. Not only have we had to create different ways of living our everyday lives, we have also had to create different ways to provide care and services to all populations. For many, there have been significant disruptions.

This issue's collection of articles on various aspects of living with COVID-19 in connection with pediatric palliative, hospice, and end-of-life care has been produced at a time when huge and unprecedented numbers of people are dying from this disease. It is also a time when the disease continues to give rise to many different challenges and to a few opportunities that touch on the interests of this publication and its readership. We hope the contents of this issue will provoke fruitful discussions about living with COVID-19 in early 2021.

This e-Journal is produced by the Pediatric e-Journal Workgroup and is a program of the National Hospice and Palliative Care Organization. The Pediatric e-Journal Workgroup is co-chaired by Christy Torkildson and Suzanne Toce. Chuck Corr is our Senior Editor. Archived issues of this publication are available at www.nhpco.org/pediatrics.

Comments about the activities of NHPCO's Pediatric Advisory Council, its e-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are currently discussing topics such as telehealth & pediatric hospice/palliative care, and inequities or disparities in pediatric hospice/palliative care for issues in 2021. If you have any thoughts about these or any other topics, contributors, or future issues, please contact Christy Torkildson at christytork@gmail.com or Suzanne Toce at tocess@gmail.com.

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Issue #62: Living with COVID-19

Click on the "bookmark" tab on the left-hand side of the PDF document for links to the following articles.

A Pandemic Perspective

p. 6

Christine Gharagozian

In this piece, Levi's mother reflects on her life after the traumatic death of her 9-year-old son two years ago and in the context of everything associated with the COVID-19 pandemic.

Self-Kindness for the Interdisciplinary Team during COVID-19: An Interview

p. 8

Interviewer: Jessica Sturgeon, MT-BC

In this article, a social worker and a chaplain are interviewed about their work in creating a six-week virtual program designed to support their hospice program's interdisciplinary team in the context of COVID-19, a program that has now become a potential ongoing support that can be utilized as the pandemic continues. The interview addresses how this program came about, why the focus is on self-kindness rather than self-care, the goals of the program, techniques used in it, comments and feedback from participants, and what might be done differently if that were possible.

Moral Distress during the COVID Pandemic

p. 13

Christy Torkildson, PhD, RN, PHN, FPCN

This article reflects on challenges arising from the COVID pandemic that lead to moral distress among those who provide pediatric palliative/hospice care and ways to respond to those challenges. The author concludes with these two sentences: "In short, the message is there are

as many ways to care for ourselves as there are to care for others. We just need to recognize the need for self-care and find what works for us, the individual.”

Isolation in COVID-19 and the Role of Home-Based Palliative Care and Counseling p. 17

Ruth Shapiro, LCSW, and Kelli Mullen Brown, MA

The authors of this article recognize that, while many families caring for children with medical complexity already had limited contact with the outside world because of their child’s mobility limitations and fragile health, the COVID-19 pandemic added new challenges in caring for that child, arranging distance learning for siblings, and meeting the economic needs of the family—all of which might be summed up in terms of increased isolation. As family caregivers reached out for help in meeting these challenges, the authors describe responses that focus on the value of anticipatory grief counseling.

Proactive Call to Parents about Their Child with COVID-19 Receiving Care at Home: Conversation Script p.20

Suzanne S. Toce, MD, FAAP

This article adapts an open access conversation guide from CAPC (the Center to Advance Palliative Care) to situations in which a child or adolescent is the patient with a complex chronic disease who has been diagnosed with COVID-19. The script set forth solicits the preferences of adult caregivers while also including the voice of the child/adolescent as pertinent. As Dr. Toce writes, a conversation of this type “can frame the issues and make sure that there is appropriate ‘disaster preparedness.’”

Rethinking Pediatric Caregiver Visitation Restriction Policies in the Era of COVID-19 p. 24

Amy S. Porter, MD, PhD

Writing as both a mother and a pediatrician, this author explores concerns about restrictive hospital visitation policies during the COVID pandemic, taking into account potential long-term psychological impacts on children and parents or other family members. Dr. Porter notes that “There is a dearth of evidence that caregiver restriction policies prevent the spread of COVID-19,” suggests that the unintended consequences of caregiver restriction policies fall unevenly on families from different socioeconomic and underrepresented minority groups, and argues that in order to build a real evidential base upon which to evaluate visitation restriction policies “healthcare systems must take a leap of faith founded in the inherent value of family-centered care to closely monitor viral spread even as they allow caregivers to accompany pediatric patients through crucial moments in their illness trajectories.”

Lessons Learned from Expanding Our Pediatric Palliative Care Team to Care for Adults p. 29

Nora E. Rahmani, MD, and Sarah E. Norris, MD, MEd

In this article, Drs. Rahmani and Norris explain that, “As COVID-19 struck New York City in March 2020 in its spread across the world, hospitals and health systems across the city, including our own, were quickly overwhelmed with a rapid influx of critically-ill adult patients. As pediatricians at the Children’s Hospital at Montefiore (CHAM) in the Bronx, New York, we watched as our adult medicine colleagues working in Montefiore’s attached adult hospital face a consistent rise in the number of patients and a corresponding decline in the numbers of beds.

We knew that it was only a matter of time before CHAM would welcome adult patients and we, as pediatricians, would have to become adult providers overnight. As we prepared for that imminent moment, it became increasingly clear that palliative care would be a central aspect in the care of our patients.” The authors go on to explain that “we were able to expand our palliative care team from one hospice and palliative care board-certified pediatrician (S.E.N.) to a team of almost 30 members, made up of pediatricians, nurse practitioners, and psychologists. Each member of the team was then assigned to one of three groups: (1) in-house consultation team; (2) supportive callers; or (3) bereavement callers.” The article touches on training members of the new team, looking to the future, and recommendations for others.

Boundaries, Burnout, and COVID-19...Oh My!

p. 33

Deborah Fisher, PhD, RN, PPCNP-BC, CHPPN

Building around a case example, in this article Dr. Fisher defines professional boundaries and explains their importance. She then suggests some strategies organizations can employ to protect their employees from work-related stress and burnout in a pandemic and concludes with thoughts about what individuals can do to promote resiliency in themselves.

Creativity during COVID-19 in Honoring a Child Who Has Died

p. 37

Ruth Shapiro, LCSW, and Kelli Mullen Brown, MA

Because pandemic restrictions altered all communal gatherings, the authors recognize that “social workers and counselors supporting families coping with the loss of a child are challenged to help grieving parents shift their family, religious, or cultural expectations of gathering to other activities that will meet their need for emotional connection and memorializing of their child.” To meet these challenges, the authors explain how “our pediatric palliative care team begins working with parents prior to their child’s death to explore practical and creative options to help them process and express their grief.” They note the importance of connections with bereaved family members and creative funeral or memorial ceremonies. The article concludes: “The current pandemic is inspiring us to create new traditions and cope in new ways that will support us long after we have returned to a world in which we can gather. Until then, creativity is the key to honoring and celebrating a child who has died.”

Virtual Memorialization Events in the Era of COVID-19

p. 40

Alice Ryan, LICSW

Annual memorial services for bereaved families to honor the lives of their deceased children are familiar components of most pediatric palliative and hospice care programs. This article explains how one children’s hospital was forced to modify its memorial services because of the impact of COVID-19. They chose to plan and implement two asynchronous services (thus allowing one for Spanish-speaking families) delivered virtually. Readers may be most interested in the details of planning and execution, along with the inter-departmental and inter-personal cooperation that was involved. But perhaps the most striking lessons appear in the article’s conclusion: “We learned many things from this experience: from the technical aspects of asynchronous recordings to letting go of outcomes over which we have no control. We learned the importance of inter-departmental collaboration and trust, and the value of open and frequent communication since we were not able to meet in-person as a planning committee.

We learned the value of simplicity. We did not have to re-invent and re-create a memorial service. We learned that we already had everything we needed to move forward. Most importantly, we learned about equity and access and the importance of inclusion.”

Funerals and Memorialization in the Time of COVID

p. 43

Buffy Peters

Writing from the perspective of a funeral service worker, this author argues for the increased importance of funeral rituals during the time of COVID-19. She writes: “[T]hese rituals are incredibly helpful for us as we begin to grieve a significant loss. One purpose of end-of-life rituals is to mark the transition from the life as we knew it to the new life we have to live after our beloved has died. These rituals also provide a container for the physical and emotional expression of grief and gives those grieving practical tasks to do to honor their loved one as they plan and prepare for them. These rituals also allow others to support the family...[and] give us opportunities to reflect on our loved one and the impact they had on our lives.” While the pandemic has imposed many restrictions on communal gatherings, this author argues that, “The key we must remember in all of this is that *we can (and must) find options within the restrictions!* It is NOT ‘all or nothing.’ We can still do *something* and that *something* is better than *nothing* when it comes to a grieving heart.” Doing something is illustrated here in considerations for funeral planning, for bringing the child’s body into the funeral home’s care, and for the funeral service itself.

Readers’ Corner

p. 47

Suzanne S. Toce, MD

In this Readers’ Corner piece, Dr. Toce reviews a 2020 article that describes how a pediatric palliative care team “adapted some of the telehealth outpatient and home hospice strategies to the inpatient setting.” She provides a summary of the article, explains who might find this article useful, points out what is special about this article, and describes where and how this information can be applied.

A PANDEMIC PERSPECTIVE

Christine Gharagozian

Levi's mother

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This present moment feels indelible and is most certainly testing my resilience. Layers and layers of both personal and collective grief and trauma. Coronavirus. The Donald Trump Presidency. California wildfires. School shutdowns and the stress of homeschool parenting. Seemingly endless screen time. Is Zoom connection a give or a take? The jury is out. Confronting the voice in my head that is so very aware of the truth that trauma lasts a lifetime. And the other voice that reminds me to actively and unapologetically seek out joy. My daily shifting and grieving to regain a sense of relative calm within my home. Ellen Bass says it so well in her poem The Thing Is. "How can a body withstand this?" I occasionally imagine that human beings all over the globe are asking themselves that question these days. In that imagining, I feel hopeful and more connected to our shared humanity. It helps. I feel lighter.

I really started asking myself that question just over two years ago as my body was assaulted by the acute grief of losing my nine-year-old son, Levi, traumatically. In those very early days, it was the only truth that made sense. So, I sat down and I screamed and I cried and I thrashed around and I wrote words like my life depended on them. Because it did. I had to learn to love the part of me that simply refused to carry on. Miraculously, I also felt immense gratitude for the brave human beings who consciously chose to sit down with me from time to time. All normal I have learned. There is nothing presentable about grief and there is nothing natural about outliving a child. The wilderness. My sense of acceptance shifts as I deepen my relationship with my grief. Presently, I accept that my heart will touch into the constant presence of Levi's absence in big and small ways as I move through each day. I also sense the softening that has entered from being so deeply humbled by my love for both of my children. My mind is relatively quiet. My emotional boundaries are strengthening. The negative emotions continue to move through me but I don't attach to them. They don't own me. My nervous system feels more flexible. I am curious about the vagus nerve and the limbic system. I am aware of the pain and deep tension that I carry in my neck and shoulders and I am realistically hopeful that this, too, will soften over time with attention and care. I imagine that the wave will continue to move to other parts and pieces of my body that aren't currently available to me. I don't look too far into the future.

In this moment, when I'm feeling into my wisdom, I am able to reflect on the never-ending miracle of loving from such a deep awareness. Such a vast improvement from the death, pain, death, pain, death, pain pulsing of my first year of life after losing my youngest son. I trust my resilience in deeper ways. It is difficult and I will get through it with as much love as I can muster on any given day. Altered. Of course. I am now able to shed unapologetically. I attempt to be a more skilled filter and consciously ask myself whether or not certain experiences feel energizing. Trees and nature are in. Donald Trump is out. Writing is in. Incessant scrolling of my

Facebook feed is out. Healthy-enough eating is in. Worry about all the things I cannot control is (mostly) out. Walking with friends is in. Avoidance is out. Hope is in. Fear is out. Boundaries are in. People-pleasing is out. Self-compassion is in. Self-judgement is out.

Maybe this valley is here to teach us how to be softer with ourselves and each other. Maybe this valley is necessary and the struggles that we are each facing individually will aid in off-loading the unnecessaries that we never truly enjoyed. Maybe this valley is here to break a few more human beings open to the truth that everything is impermanent. Everything. Maybe the animals on the planet are breathing more deeply in this season of slowing down. I don't know. But I'm curious about this valley and I'd like to stick around for a few more years to find out.

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SELF-KINDNESS FOR THE INTERDISCIPLINARY TEAM DURING COVID-19: AN INTERVIEW

Interviewer: Jessica Sturgeon, MT-BC

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Interviewing:

Jenifer Heseltine, LMSW, and Rev Karen Hale, M.Th.

Living with the Coronavirus (COVID-19) pandemic of 2020 has no doubt been a difficult year at the local, national, and global level. The World Health Organization (WHO) and a variety of independent researchers have cited the increase in PTSD, grief, and burnout in health care workers as a result of the effects of COVID-19. In turn, COVID-19 has been identified as a risk factor for increased stress that can lead to depression, anxiety, and other mental health disorders (Spoorthy et al., 2020). There has been an evident physical, mental, and emotional toll on health care workers with an undercurrent of worry for the impact this has on the care provided to patients, clients, and families. To combat this, many organizations have utilized creative strategies to provide additional support to staff.

At Seasons Hospice Connecticut, two members of the supportive care staff created a six-week *virtual* program to better support the interdisciplinary team. This short, closed-ended program has now become a potential ongoing support that can be utilized as the pandemic continues.

How did this idea come to fruition?

Jenifer: Honestly, this was something that we were interested in doing in the past and had presented to our local leadership because hospice is challenging in itself. We were, and are, in a collective trauma with the coronavirus pandemic. With COVID, this became even more pressing for us to advocate for and actually do for our colleagues.

Karen: We recognized early on that this particular health care challenge had the possibility of creating unhealthy and prolonged levels of anxiety and fear amongst our patients and families, co-workers, colleagues, leadership, family, and friends. In any direction we turned, COVID touched something or someone and we needed a plan.

As clinicians, what have you noticed about the mental and emotional strain in members of the IDG?

Jenifer: Reactivity! I think the biggest challenge that I have seen and continue to see with staff is that because anxiety levels are heightened, tolerance is low. I've also witnessed aspects of self-abuse going on, even outside of hospice and the IDG. In this world, we see that if we haven't "come out of all this" without doing something good or having a new skill, then we have failed.

Karen: The mental emotional strain on hospice care workers and their families after COVID will be far reaching. Feelings of confusion, helplessness, and insecurity are often compounded by the input of our communities, culture, and media. It is safe to say we will need to be prepared to address the PTSD created by this pandemic. The COVID epidemic continues to shape and mold each and every person whose vocation is connected to health care and most especially hospice and end-of-life care. Protecting the mental, emotional, and spiritual safety of each hospice caregiver is our responsibility. We must remember that moral injury is very real.

You frequently use the phrase "self-kindness" rather than "self-care"; why is this?

Karen: The old adage, "You cannot pour from an empty cup."

Jenifer: For me, it was a personal experience that truly shaped my mindset on the difference between self-care and self-kindness. I feel that "self-care" has become a buzz word and can become this self-abuse. While completing my master's program, which was challenging while I was also co-parenting, working through my internship, and practicing as a yoga teacher, I was experiencing panic attacks (and the associated shame because I'm a yoga instructor, of all professions). When people would say "You HAVE to practice self-care," that became a trigger for me. Then I was in a course with a professor who gave the class an assignment: to write on the fridge how they were going to be practicing self-care, look at the tasks listed, and then check off each task once you had done it. That was the tipping point for me. It broke my heart that other people were going to stare at the list on the fridge and see tasks they would not be able to check off. This idea of self-kindness was formed in my mind. By not working on these "tasks," we can be more present for those we serve and for ourselves. It's not about being productive and the quantity or quality of the care you provide yourself—it's about giving yourself grace.

As a social worker and chaplain (respectively), what was your goal in creating this support?

Jenifer: My goal was melding together my experience and practice as a social worker, yoga instructor, and mindfulness teacher. My hope was to offer suggestions of tools for our staff to help them stay present and responsive rather than reactive. I also knew that this time would offer a calming break in the day. We really are all in this together and we need to be mindful of our own feelings of distress, fear, anxiety, etc. Then, and only then, can we lean into it.

Karen: As the chaplain on the program I recognized, our team members with their sense of obligation to their patients and families, that their calling and vocation would be their driving force during the pandemic. Their physical, mental, and emotional needs would take a back seat to their sense of “this is what I was built for” attitude. This attitude was particularly true for our frontline nurses and hospice aides. Creating a space for the interdisciplinary team members to be able to express their fears, feelings, hopes, and desires weighed on my heart tremendously. We needed to create a sacred space where we could recognize each individual person. It was important that we created a platform that would give a voice to their courage, selflessness, and self-sacrifice. Our weekly program became a powerful tool to decompress, become grounded and create space for those attendees to speak their truth, even if just for that hour.

Can you describe the techniques that were utilized within this program?

Karen: The goal each week was to offer a word or two that would promote resiliency, mercy, and strength in spirit. The program was called A Healing Hour. Each week we were prepared with a reading, a time for grounding through meditation or guided imagery and a closing that would offer empowerment for the days ahead. For example, a very simple mindfulness practice called Metta Meditation addressed the experience of a mind “FULL” or “Mindfulness.” We used this following meditation: *May I be peaceful, May I be happy, May I be well, May I be safe, May I be free of suffering. May all beings be peaceful, May all beings be happy, May all beings be well, May all beings be safe, May all beings be free of suffering.* We also looked into Maslow’s hierarchy of needs and talked about the recreated version: physiological, safety, love, belonging, esteem, and actualization

(<https://ecampusontario.pressbooks.pub/profcommsontario/chapter/your-interpersonal-communication-preferences/>).

As clinicians, we were very aware of the need to face the mental emotional strain of living and working in a permanent state of fight or flight response. Our overall focus was to create a neutral safe space. Space was needed to talk about the challenges of the day, the week, or even the hour. Our discussions remained open-ended and never rushed. Each hourly program was designed around a word or two such as peace, balance, hearing yourself and your body’s needs, taking care of you, and often providing deep active listening and saying *I hear you*. We talked of compassionate tenants one might connect with. Each session had an intentional beginning, middle, and end. Each technique was thoughtfully chosen in order to face the anxiety, sadness, and confusion, grief and mourning, guilt (whatever the feeling) head on so that by the time the hour was over the staff felt nurtured and hopefully more confident for the days ahead.

Jenifer: We worked hard to make sure the group was a safe and welcoming place where people could choose to have their web cameras on or off, speak or not, and respond at their level. We were fortunate in that both Karen and I worked well together and were able to trade off responsibilities so we could also practice self-kindness in the way we

approached this extra project. Due to my training, I was able to provide guided meditations, love and kindness meditations, progressive muscle relaxation, and breath work in using the breath to activate the parasympathetic nervous system. We took a very trauma-informed approach in designing the format and utilizing techniques. As time went on, we were able to pull in our music therapist to provide music and imagery techniques and other relaxation-based support.

What are some of the comments or feedback that you both have received?

Jenifer: One of the most memorable comments I received was, “I did what you told me and it really worked! I thought I was going to lose it, but it worked.” To me, this meant the world because we were able to provide a space of learning and healing. It’s a win-win for everyone. At least one member of the group and IDG was able to thoughtfully stop, identify, and alter their mindset to avoid reactive behavior. It hits me that this program served as more than healing and rest; it was also a form of psycho-education for those that just don’t know any way different than what they’ve done their whole career or lives.

Karen: The feedback for our six-week virtual program was incredibly positive and genuine. Thankfulness! Peace and replaced energy! Many attendees shared that the programs touched them personally and professionally. Our program has continued with a moment of self-care and compassion during our weekly IDG meetings. Some shared that the time together was a ritual they looked forward to. Many intentionally scheduled this time within their day—even if they could only listen. Most recently, a few staff nurses revisited the materials and have asked if the weekly sessions might be resuming. In such a time of *unknown circumstances* our supportive care team felt a sense of contentment knowing we made a difference.

Do you have hopes or inclinations about the potential benefits of instilling a supportive program such as this in other hospice or health care programs?

Jenifer: My hope is that we can start reminding ourselves that we also need and deserve support like this. We are in the trauma—we don’t know we need the help now—but this provides the space and introduction into getting some of what we need to get through the day. How is it that you see this person or this family in front of you as being worthy of help and support, but you somehow are not. No matter where you are, give yourself permission to give to yourself.

Karen: If we are committed to our staff and volunteers’ self-care, self-kindness, self-compassion, and overall wellness, we must be willing and able to recognize the sacrifice of our hospice care providers. We must be willing to go the extra mile to develop strong, relevant, supportive programs that have the ability to address suffering, create space and meaning, and eventually enable empowerment to those working on the front lines.

What would you do differently, given the chance?

Karen: As a hospice chaplain I would have started the program earlier. It is my hope that we will offer this program quarterly and look beyond the weekly IDG meeting. This program was a powerful example how we can find meaning, bring hope, and sow mercy.

Jenifer: The most difficult aspect of this program was the necessary evil of technology. Virtually engaging can be so hard because connection is so minimal. We have our cameras on, but we can't demand others do so because they may need to have that time. It was hard to give energy without the feedback. Despite this, a benefit is remembering and being mindful that *our* experience doesn't dictate the experience of others. If we were able to continue this program in the future for any length of time, I would love to expand and integrate new and more extensive aspects to be themed and helpful. This would include the tendency of reactivity rather than response because it can create a feedback loop that can become very dangerous.

Self-Kindness is a concept that can greatly strengthen the support provided to ourselves and to the patients and families that we serve. Although the pandemic has resulted in less ability for socially-based strategies to be practiced, the program utilized at Seasons Hospice Connecticut provided a way to promote individual growth and awareness in a socially-acceptable manner. Further, the strategies taught and practiced provided additional means for the interdisciplinary team members to "fill up their cups" so they can continue to pour compassion into their patients and families.

References

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MORAL DISTRESS DURING THE COVID PANDEMIC

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When I first sat down to write this piece, I thought I would knock it out in no time. However, I found myself staring at the page and then rereading articles, interviews, and blog posts, reviewing presentations and notes, trying to focus. Realizing there was so much information and so many tangents that I put it away to think about. This is just one perspective on a topic that is changing by the day not only due to the evolution of the pandemic and the impact it has made to every facet of our life, but also due to all aspects that affect our lives and sense of what is right and wrong.

What is moral distress? An early definition by Jameton is, “Moral distress occurs when a healthcare provider knows the right thing to do but constraints make it impossible to pursue it.”¹ There is a great deal of literature on this topic and several connotations of and discussion on what constitutes moral distress.^{2,3} The definition that resonated with me is by Rushton and colleagues, “The pain or anguish affecting the mind, body or relationships in response to a situation in which the person is aware of a moral problem, acknowledges moral responsibility and makes a moral judgement about the correct action; yet, as a result of real or perceived constraints, participates in a perceived moral wrongdoing.”⁴

There have been countless articles, interviews, blog posts, etc., that highlight the anguish healthcare providers are feeling during this pandemic. Anguish at the number of individuals dying, anguish because individuals are dying alone, anguish at the impotence that the pandemic has caused us not to be able to provide care in the way we feel is best; anguish at the distance the pandemic has forced in both our professional and personal lives. In pediatrics, the primary cause reported has been the limitations of visitors, especially when a child may be or is dying. There is a viral video of a dad dressing in different costumes each day, dancing in the hospital parking lot where his child could see him from his hospital room window to remain connected and bring a smile to his face since dad was not allowed to visit as mom was the designated family member for their child who had just been diagnosed with cancer. Additional causes of distress that have been reported include pediatric staff being required to care for adult patients, as well as limited supplies/equipment and the increased barriers to services.

In practice, ethical dilemmas have often been identified by the amount of moral distress a situation caused. One means to obtain support and a sense of meaning could be with an ethics consult. I highly recommend turning to your Ethics Committee when there are situations causing moral distress. If you do not have an Ethics Committee, there still are resources to assist you (please see references and resources listed at end of this article). If you do not have

an Ethics Committee at your organization, I encourage you to work with your organization to start one!

Certainly, some of these situations are not unique to the pandemic; however, it is clear that the emotional strain, the unknown outcomes, and the constant change to what was “normal” simply adds more stress, which can lead to increased suffering and moral distress. There has always been a fine line between moral distress and emotions, especially when working with children. There are many factors that contribute such as our own family and personal history, our beliefs, values, assumptions, as well as our culture, ethnicity, and religion and our conscious and unconscious biases. All of this impacts our relationships with our patients, their families, and our colleagues; how we see them and how they see us—and how we respond to any situation.

Being aware of our feelings and whether our feelings have become factors that influence our view of a situation is critical. This is where being able to debrief, to review the situation that is causing distress, is so important. If a team is not able to do so in a calm objective manner, seeking an Ethics consult is highly recommended. As noted earlier, an Ethics consult is a source for education and support; Ethics Committees do not dictate action but do look at a particular situation through different lenses and provide guidance, not direction.

Another example that has caused significant distress during the pandemic was the decision to not perform CPR on anyone unless there was appropriate staff with full PPE due to the airborne transmission of the COVID virus. This was also true for our EMT staff in the field; they were not to perform CPR unless in full PPE to minimize airborne transmission which is significantly increased during cardio-pulmonary resuscitation. This policy was put into effect not only for home care providers but also in outpatient clinics serving both adults and children throughout the United States. For many, this mandate was simply sent out through organizational email messaging as a new policy to be implemented immediately with little to no explanation or education. At my organization, this caused significant distress as well as fear of liability. An additional source of distress has been the focus on healthcare providers first, rather than patient first—our usual mantra.

Caregivers, perhaps especially professional caregivers, find it difficult to prioritize the caregiver rather than the patient. It is for many a complete about-face to our normal. The Center for Medicare and Medicaid services started their exemptions allowed during the pandemic with “Patient First” (<https://www.cms.gov>)—allowing for exemptions to regulations in order to continue to provide services to patients while decreasing regulatory restrictions. However difficult, simply put, if we do not care for the providers first, there will not be anyone to put the patient first. This can also add to our sense of discomfort, of distress.

Providing education, reviewing ethical principles, and taking into account scientific data on CPR outcomes and statements from multiple professional organizations such as the consensus statement from the American Heart Association and the Center for Disease Control helped our staff to understand the rationale behind the decision to not perform CPR unless fully prepared

with appropriate PPE. This new focus on healthcare providers has caused significant distress to many, both professionals and non-professionals alike. Providing a safe space for staff to share their feelings proved to be a critical source of support for our staff. Our Ethics team as well as our chaplains and social workers were of significant help for our team members.

In palliative and hospice care we provide many different therapies/modalities to help our patients and families with their journeys. We have found that integrating different therapies historically offered only to patients and families to our staff has provided different ways for staff to practice self-care. These included writing/journaling, art therapy, pet therapy, guided imagery, mindfulness and resilience training, virtual potlucks, pet therapy, and many more—the unifying theme was reinforcing the human connection and community. Reinforcing that no one was alone in their work and although accentuated by COVID-19, I believe the need to not be alone is true for anyone who works in a high stress/highly emotionally taxing field such as pediatric palliative and hospice care.

The human connection and sense of community is crucial; the need to be able to debrief privately is also important. Most organizations have employee assistance programs which can provide opportunities for private support and may be of more benefit for professional support. In short, the message is there are as many ways to care for ourselves as there are to care for others. We just need to recognize the need for self-care and find what works for us, the individual.

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ISOLATION IN COVID-19 AND THE ROLE OF HOME-BASED PALLIATIVE CARE AND COUNSELING

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While the advent of COVID-19 in early 2020 resulted in dramatic lifestyle changes for most people, families caring for children with medical complexity faced a unique set of challenges. Many families already had limited contact with the outside world due to their child's mobility limitations and fragile health. However, the extremes of this new situation placed a significant strain upon caregivers as they sought to protect their vulnerable child, while also balancing new responsibilities around distance learning for siblings and the overall economic security of the family. During this time, Coastal Kids Home Care home-based palliative care teams offered invaluable relief through responding to the practical and emotional challenges faced by children and caregivers alike.

In the early days of the shelter-in-place, many families initially responded by further isolating themselves. Some chose to discontinue shift nursing and expressive therapies and requested only telehealth visits for social work. These families had long been accustomed to the fear that a simple "cold virus" could put their child at risk of a prolonged hospitalization and even death. While this experience has allowed them to develop coping skills and build resiliency, the intensity of COVID-19 also heightened feelings of anxiety and brought with it a new set of concerns around access to healthcare for their child.

For children in treatment for cancer, or with other emergent medical needs, visits to clinics and even hospitalizations were sometimes unavoidable during the pandemic. Many physicians and facilities began to require COVID-19 testing for patients prior to appointments. For these families this meant extra trips to distant specialty hospitals and uncomfortable tests. If a child did require hospitalization, new protocols around visitors meant that patients were only allowed one visitor for the duration of their stay. This put a burden on parents who were now pulled between their desire to be at the hospital and advocate for their child, and the responsibilities for work and other children at home. Further, despite rigid protocols, parents

often expressed concerns around exposure to the virus for their children and themselves during hospital stays. The overall intensity of accessing health care, and especially hospitalization, has dramatically increased during the pandemic. As a result, families with medically fragile children are relying on in-home care options to meet their child's needs.

By summer, many caregivers began to reach out to their home-based palliative care teams for renewed connection. Shift nurses were welcomed back into patient homes, parents requested art and music therapy or child life services for their child, and some sought counseling support for themselves and other family members. During the pandemic there has been an 18% increase in the number of patients and family members who wish to utilize the anticipatory grief service of Coastal Kids Home Care's home-based pediatric palliative care. As the whole world copes with one of the most stressful periods in recent history, access to a trusted therapist who can safely visit their home or provide counseling via telehealth is a valuable resource for struggling families.

Due to their training and experience, grief counselors are uniquely qualified to address both the broader impacts of the pandemic and the specific issues around caring for an individual with a serious illness. Counselors can provide active listening and validate feelings, while also providing strategies to help a person *function* while they are feeling anxious or overwhelmed. For many caregivers, the pandemic has exacerbated feelings of loss and loneliness. Parents and siblings are unable to connect with friends and family members to talk through feelings, or simply take a break from their caregiving responsibilities. Turning to a counselor, who they can access via telehealth or in a safe home visit, can become a lifeline.

One recent story illustrates the critical role of grief counselors during this unique time. This spring, a 15-year-old boy was referred to Coastal Kids Home Care for anticipatory grief counseling. His mom was living with renal disease and was in an outpatient palliative care program while she waited for surgery to prolong her life. The counselor continued to see the teenager, building a trusting relationship with him. Early this fall, the counselor received a sudden call from the boy's mother. She had been diagnosed with COVID-19, she was hospitalized and likely would not survive. Knowing that she would not be able to see her son before she died, she asked the counselor to support him through her loss. As she struggled for breath, she expressed relief that her son would have support through this difficult period. For the son, this was not only the loss of the parent he felt closest too, but also the loss of hope for the future and faith in the world. After testing positive for COVID himself, with only one other family member at home, his counselor became a beacon, providing him with a path of connectedness during this intensely physically and emotionally isolating time.

Caring for a medically fragile child, or living with an individual with a serious illness, is a very isolating experience. Add a worldwide pandemic and that experience can become overwhelming. Many families who depend on home-based palliative care services have developed coping skills to achieve peace amid uncertainty, or joy despite the devastating reality of their child's medical condition or intense caregiving responsibilities. However, persistent isolation and pervasive fear is taking its toll. Coastal Kids Home Care home-based palliative care

services have offered critical connection to safe and trusted home health care for children and social work support and counseling for the whole family.

The benefits of anticipatory grief counseling have proven significant during this unique period of time. Beginning at the time of diagnosis, pediatric patients, caregivers, and siblings are able to work with a counselor to identify and grieve the many losses that come with a terminal or chronic illness. As we begin to experience the loss of a child's appearance, their voice, or participation in the family activities, anticipatory grief counseling can help manage the associated feelings and can also help the caregiver achieve better physical and psychological health, as well as improved quality of life following the death of a loved one.¹ Experience has shown that the opportunity to access anticipatory grief counseling during this time of extreme social isolation has proven crucial to achieving better outcomes for families and caregivers.

It is notable that caregivers who utilized anticipatory grief counseling prior to their child's death were much more likely to continue with bereavement counseling following their loss. This is especially true when a caregiver continues with the same counselor through their grief journey. Almost all of them continued counseling after their child died, sometimes adding family members to the counseling services who were not as open to it prior to the death. Our family-centered approach acknowledges that bereavement counseling for child loss, and all loss, must be offered with no time limit. This is perhaps even more critical in a year of widespread trauma and loss.

As vaccinations roll out to healthcare workers and vulnerable populations and we begin to see a light at the end of the COVID-19 tunnel, our communities will face a collective grief over loss of life, jobs, and expectations for the future. Together, we can learn from families caring for medically fragile children who have developed resiliency in the face of incredible uncertainty. Acknowledging the experience of grief and identifying individual coping skills such as prayer, exercise, or journaling is critical. However, recognizing the inherent value of human connection, from safely gathering with family and friends to accessing counseling or participating in a COVID-19 specific bereavement groups will be essential going forward. As a community we can develop and express empathy for each other, while also validating the experience of social isolation that occurred for everyone during COVID-19 and will continue for families caring for our communities most fragile children well into the future.

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PROACTIVE CALL TO PARENTS ABOUT THEIR CHILD WITH COVID-19 RECEIVING CARE AT HOME: CONVERSATION SCRIPT

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One of the most important parts of advance care planning is to make a plan for the “what ifs.” One of the most important contingency plans during the SARS-CoV-2/COVID-19 pandemic is a plan for care of a child or adolescent with a complex medical condition who contracts COVID-19. How does the child/adolescent wish to be treated? What will be the site of care? Who will be the caregivers beyond the family? What resources including supplies may be required and what will be the source of the supplies?

CAPC (the Center to Advance Palliative Care) has published an open access conversation guide that I have adapted to the case where a child or adolescent is the patient with a complex chronic disease who has been diagnosed with COVID-19.

Pediatric palliative care (PPC) team member	Parent/caregiver
1. Check in	
I’m calling from the _____ (PPC program). How are you doing?	I’m ok, just worried about _____ (child/adolescent)
2. Ask about COVID	
I understand from your _____ (regular key contact from the PPC program) that _____’s (your child’s) main problem is _____. Do I have that right?	Yes, she/he has been dealing with _____.
I also understand that _____ (child/adolescent) has tested positive for COVID.	Yes
I can imagine that when your family has been dealing with all the previous problems hearing about her/his COVID must be worrisome.	Absolutely; we’ve been listening to the news nonstop.
3. Lay out the issues	
I am hoping that _____ (your daughter/son) does well and is not affected significantly by COVID. I also want to make sure that we at the	OK. We haven’t been sure what to think.

PPC program provide the care you want if _____ worsens. Could we talk about that?	
Even when people get COVID, many have an illness that is mild to moderate and don't need to be in the hospital. That is a better case scenario. I hope _____'s (your son's/daughter's) case of COVID turns out be mild.	Me too.
Could we plan for the worst case, too? Here is the issue. We know that when people who already have a serious illness or condition get a severe case of COVID, the COVID almost always takes their life.	Oh my gosh.
I wish things were different.	Yeah, me too
I worry that if _____'s (your daughter's/son's) COVID becomes severe, there is a high chance it would take her/his life. Given that, would you still want your child to be in the hospital? Would _____(she/he) want to be in the hospital? I am asking because the hospital is going to be very different than usual. Families have found that the restrictions on visiting have been very difficult.	OK.
Coming to the hospital may not be the best care for _____(your child). Some families in this situation would rather have their child/adolescent stay at home and have care that comes to them.	That actually makes sense to me.
4. Motivate them	
You can tell me that, IF your child's COVID got severe, you would rather not have them come into the hospital and have care at home or you could tell me that you do want to bring them to the hospital. You can change this anytime. What are your thoughts today?	Uhh...This is a lot to take in. I am leaning towards not bringing _____ to the hospital.
5. Including the child/adolescent Have you spoken with _____ (your son/daughter) about their wishes if his/her condition worsens? Most children with chronic conditions have a much better understanding than one might expect. I recommend that you include _____ (him/her) in your family discussions.	We'll have a family meeting tonight and inquire about what _____'s (child/adolescent's) wishes are.

6. Expect emotion	
This is a horrible epidemic, and I wish things were different.	It's hard to say, but we don't want any of our family to be separated from _____(our child) as he/she is dying.
I want to honor your and _____'s (your child's) wishes.	Thank you
I respect what you are saying. What that means is that you would rather not have your daughter/son come to the hospital and potentially be separated from some of their family. To be prepared, you should talk with your primary PPC provider so that you can make further plans to have adequate services and supplies available if her/his condition worsens.	That's the plan for now.
7. Record	
I'll write a note in the chart so the whole team is aware of the current plan. OK?	OK

Soliciting the preferences of the adult caregivers (usually the parents) is generally the initiation of the conversation. It is important to include the voice of the child/adolescent, as pertinent. For cognitively intact minors, most have an awareness of their condition beyond that expected by their age. In all of these cases, their input should be sought, and the child patient should be involved in decision making consistent with their preferences.

Once a plan is in place, if home is the preferred site of care, it would be appropriate for the parents to ensure that appropriate health care personnel and supplies are available to meet the needs of the child if the condition worsens. In underserved areas, this can be quite a challenge so advance planning is key. A conversation between the parents and the child's/adolescent's current health care providers can frame the issues and make sure that there is appropriate "disaster preparedness."

Resources

CAPC Response Resources Hub: <https://www.capc.org/covid-19/>. *Excellent resource that helps guide the (adult) palliative team in multiple areas. These CAPC resources are open access—free and open for all to use. Don't miss the opportunity to utilize these COVID pertinent resources!*

CAPC Proactive Call to Patients with COVID-19 About Receiving Care At Home: Conversation Script: <https://www.capc.org/covid-19/proactive-call-patients-covid-19-about-receiving-care->

[at-home-conversation-script/](#). *This is the open access CAPC resource upon which this adaptation was based.*

Van Breemen C, Johnston J, Carwana M, Louie P. Serious illness conversations in pediatrics: A case review. *Children* 2020 Aug 18;7(8):102. doi: 10.3390/children7080102. Open access: <https://www.mdpi.com/2227-9067/7/8/102/htm>

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RETHINKING PEDIATRIC CAREGIVER VISITATION RESTRICTION POLICIES IN THE ERA OF COVID-19

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When the COVID-19 pandemic surfaced in March 2020, I was just weeks postpartum and on parental leave from my role as a Fellow in Pediatric Complex Care. Both a mother and a physician, I immediately worried about how children would be affected by the virus, not just by SARS-CoV-2 infection but also by the social sequelae of our society's fear of infection.

Debriefing with a friend and colleague on the frontlines, I learned of one pediatric hospital's policies on visitation of pediatric patients: If a patient was on the regular nursing floor, one parent or guardian could be at the bedside for the entirety of the hospital stay, as long as he/she/they did not leave the room at all, for fear of spreading the pathogen. In the Pediatric ICU, no one could accompany the sick child because there are no bathrooms connected to the individual bays and thus not leaving the room would be impossible. I was horrified. How could families be kept from their seriously ill children's bedsides?

As a mother, I agonized over the visceral pain of separation between parent and child, especially in moments of hardship and illness. As a pediatrician, I wondered what long-term psychological consequences there would be for children whose siblings, parents, or grandparents died before they had a chance to say goodbye. As a physician training in complex care and planning further training in palliative care, I anticipated wrenching decisions among critical care and palliative care teams determining which family members could spend patients' final moments with them in person, versus solely mediated by internet. Weeks later, upon returning to clinical care at the pediatric long-term care facility where I work, I witnessed families unable to visit their resident children for weeks or months and patients alone in emergency rooms with parents learning of critical diagnoses via FaceTime, unable to offer physical touch to their children. My pediatric palliative care colleagues shared stories of mothers alone in NICU cubicles worrying their babies will never meet their siblings and fathers missing their children's final moments while waiting for their turn to hold vigil at the bedside. Separating pediatric patients from those who love them most renders the most excruciating moments unbearable.

I spoke with Sam [names of all patients and family members mentioned in this article have been changed to protect their identities], whose infant daughter, Sarah, was diagnosed with progressive cancer in March 2020, just days after the COVID-19 pandemic arose. "The thing that got me most was that...I was only allowed to be there for a set number of days; then I had

to go home,” he explained. Sarah’s grandparents and uncle were each only allowed to see her for a few minutes over the course of her illness and through her end of life. Sam described how when Sarah was transferred to a different hospital for higher level care, her nurses had to band together to motivate for a three-day pass for Sam to accompany his wife at Sarah’s bedside. After several days at home, unable to support his wife in person or hold his critically ill daughter, Sam made it back to the hospital—just hours before Sarah died. Tearful, he shared with me: “My wife—we are usually there for each other—but she had to handle a lot of it by herself. Nobody should have to deal with that alone.”

My doctoral work in social and medical anthropology unpacked the social, political, and economic underpinnings of the dual epidemics of HIV and tuberculosis in South Africa, as well as the influence of the international rush to manage them with the fury of colonial conquest. There is a long history of fear of contagion causing social, political, and economic discrimination in epidemic landscapes.¹⁻⁴ The alarm I felt in response to policies separating patients and families in the name of epidemic containment was grounded in studies of epidemic history.

Over the last year, as millions have been hospitalized across the United States and worldwide, healthcare systems have enforced policies aimed at preventing the spread of coronavirus by restricting caregiver visitation. Many such policies were enacted shortly after the emergence of SARS-CoV-2, in reactionary fear of viral spread, and have yet to be revised to account for a more nuanced understanding of this particular strain’s epidemiology. The effects of such policies on patients, families, and clinicians have been overwhelming; many have suffered and died alone. Even as the moral distress incurred has been recognized,⁵ it has been framed as an inevitable repercussion of infection control.^{6,7}

There is a dearth of evidence that caregiver restriction policies prevent the spread of COVID-19. Several major academic medical centers report adequate infection control despite allowing two caregivers with pediatric patients, though, to date, there is no rigorous scientific evaluation of such variation in policy. My colleagues and I worry that more rigorous evaluation of caregiver visitation restriction policies that were implemented in the context of urgency and uncertainty at the start of this pandemic will reveal that the unintended harms they caused far outweigh the intent to mitigate the spread of infection.⁶ In the meantime, as the pandemic blazes through communities nationally and globally, we owe our patients, their families, and our colleagues serious consideration of alternatives to caregiver restrictions. We cannot let down our vigilance in protecting patients, families, and healthcare workers from the virus, and simultaneously, we must ensure that infection prevention measures align with the core principle of pediatrics—to always provide care in the best interest of the child.⁶

Keeping in mind the assumption that primary caregivers (most often parents) are essential for providing good pediatric care, we, as healthcare workers, must rethink our caregiver visitation restriction policies for three reasons: First, primary caregivers are the pediatric patients’ best advocates; not only can they interpret the child’s needs and discern signs of distress better than anyone else, but they also know the intricacies of a child’s medical history.⁶ In fact, the literature on patient safety suggests that primary caregivers’ intuition is critical in preventing

medical errors.⁸⁻¹⁰ Second, the family unit's well-being is essential to the child's well-being, a concept that holds true in all medicine but originated in pediatrics. In fact, pediatrics integrates "family centered rounds" and "family meetings" into regular inpatient hospital practice because pediatric practice starts with the premise that the health of the child depends on support from the family unit. Third, disconnection from their sick children can compromise the health of primary caregivers by causing tremendous stress and anguish. Of course, primary caregivers of children with serious illness are at high risk for mental health problems,¹¹ and such threats are intensified when they are prevented from being physically present with their children through suffering and uncertainty.^{12,13}

Restricting caregivers from accompanying their sick children is fundamentally opposed to the centrality of family that is intrinsic to the practice and teachings of pediatrics and presents ethical uncertainties—and concomitant moral distress—for pediatric clinicians caring for the sickest children.⁶ As the COVID-19 pandemic has surged throughout the final months of 2020, pediatric clinicians have become progressively more distraught over policies limiting caregiver visitation, communicating their concerns via social media, blogs, and peer-reviewed journal articles.⁵ Often, policies are implemented in a top-down way, without buy-in from the clinicians witnessing first-hand the ramifications of separation between child and caregiver. Many institutions are willing to grant exceptions for individual patients, allowing two parents at the bedside when a child is at the very end of life or letting an adolescent sibling who can reliably wear a mask visit briefly for a final goodbye. No doubt such accommodations help in some instances—but often cannot be put into place quickly enough when a patient's clinical status worsens suddenly. Memory-making, farewells, and moments of connection become missed opportunities.

The unintended consequences of caregiver restriction policies do not fall evenly on all families from different socioeconomic and underrepresented minority groups.⁶ Just as fear of contagion from people living with HIV has contributed to discrimination and poorer health outcomes,¹⁻⁴ caregiver restrictions driven by fear of COVID contagion disproportionately disadvantage those already struggling with the systemic social injustices of poverty and racism. Even as policies are applied equally to all families, their ramifications yield inequity.⁶ That is, a single parent of several children may not be able to split her time between the hospital and home in a setting in which COVID-driven hospital policies do not allow siblings to join her at the bedside and COVID-related precautions make it dangerous for a family member to watch the other children. A father who is not allowed to stay in his child's hospital room for an extended period of time cannot cover the cost of daily transportation between hospital and home, leaving him to only visit once weekly despite his son's tenuous health status. Barred from the bedside, the grandparents without the financial means to pay for reliable, fast internet access are unable to connect virtually with their dying granddaughter. Prejudiced, moralizing conclusions are drawn about the Black mother who is always alone at her infant son's bedside or the Latinx father who only visits his child in the PICU once a week. Caregiver restrictions aggravate hardships faced by those already dealing with socioeconomic stress and racial discrimination.

Collectively, we must hold ourselves accountable for thwarting the spread of SARS-CoV-2, and an essential part of prevention is the design and implementation of safe visitation guidelines. Nonetheless, healthcare systems should seek alternatives to policies preventing primary caregivers from staying with hospitalized children at bedside. More attention is needed to determine what safety measures can prevent viral spread among visitors (i.e., mask wearing, handwashing, limited movement between a patient's room and other hospital spaces), so that primary caregivers can safely be present at bedside. Learning from specific case-by-case experiences over the past year, hospitals should work to standardize clinical triggers for loosening visitation protocols, including critical illness, accelerated worsening of clinical status, or end of life.⁶ Most central to the process of revising the current policies is to proactively involve clinicians caring for pediatric patients on the frontlines—as well as bereaved parents and parents of chronic, complex, and critically ill children—as key stakeholders in policymaking, so that policies reflect clinical and interpersonal realities. Such partnership will not only improve the quality care but also has the potential to allay moral distress among clinicians.

With individual case studies amassing into small but powerful data sets and several academic medical centers taking the lead in loosening caregiver visitation restrictions, we are starting to accumulate data that suggests that allowing two or more caregivers at the bedside does not worsen viral spread. To build a real evidence base, however, healthcare systems must take a leap of faith founded in the inherent value of family-centered care to closely monitor viral spread even as they allow caregivers to accompany pediatric patients through crucial moments in their illness trajectories.

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LESSONS LEARNED FROM EXPANDING OUR PEDIATRIC PALLIATIVE CARE TEAM TO CARE FOR ADULTS

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As COVID-19 struck New York City in March 2020 in its spread across the world, hospitals and health systems across the city, including our own, were quickly overwhelmed with a rapid influx of critically-ill adult patients. As pediatricians at the Children's Hospital at Montefiore (CHAM) in the Bronx, New York, we watched as our adult medicine colleagues working in Montefiore's attached adult hospital face a consistent rise in the number of patients and a corresponding decline in the numbers of beds. We knew that it was only a matter of time before CHAM would welcome adult patients and we, as pediatricians, would have to become adult providers overnight. As we prepared for that imminent moment, it became increasingly clear that palliative care would be a central aspect in the care of our patients.

Given the need to social distance and limit the spread of COVID-19, we were faced with the challenge of how to maintain compassionate, humanistic care in the midst of the pandemic. Stories from across the globe highlighted the difficulty encountered by patients, families, and healthcare workers alike, as patients and their loved ones were forced to separate during an already frightening and trying time. It was truly heart-wrenching to think of the patients that would be dying alone without a loved one at their bedside to hold their hand and support them in their last moments. Therefore, as highlighted in the article "Pediatric Palliative Care When COVID-19 Positive Adults Are Dying in a Children's Hospital,"¹ published in *Pediatrics* in September 2020, we rapidly expanded our palliative care team.

As described in the article, through CHAM's deployment system, we were able to expand our palliative care team from one hospice and palliative care board-certified pediatrician (S.E.N.) to a team of almost 30 members, made up of pediatricians, nurse practitioners, and psychologists. Each member of the team was then assigned to one of three groups: (1) in-house consultation team; (2) supportive callers; or (3) bereavement callers. The unique roles and responsibilities of each group are described in the *Pediatrics* article. Training for these roles was conducted

virtually, going over basic palliative care assessment tools, phone scripts, and spiritual assessments that could be used by the team over the phone. The training also included guidance on note writing and the review of templates that were developed to streamline notes to allow for consistency in the notes and to help guide conversations. Given the emotional strain of such work, support systems for both the palliative care team members and the primary medical providers was established as well. The care that the palliative care team provided proved to be successful and vital both in the care of patients with COVID-19 as well as the support of the primary medical teams.

With the end of the first wave of COVID-19 in New York, the members of the palliative care team went back to their standard time roles. Now, with the rising numbers of COVID-19 cases in New York and throughout the United States, the team at CHAM is preparing for a second surge. Over the past several months we have received a great deal of positive feedback from staff, patients, and families. The essential structure and function of the expanded team was successful in meeting our goals of providing and supporting the highest level of care at the bedside and through bereavement. We are fortunate that all prior team members have enthusiastically agreed to return to this service, if redeployment becomes an institutional necessity once more.

What went well? The expansion of our team would not have been possible without the support and commitment of Dr. Michael Cabana, Chair of Pediatrics at CHAM, who personally helped recruit our team members. Patients and family members have shared that they appreciated the daily contact with our team and the chance to be heard. They found their conversations with the members of the palliative care team to be a safe space to ask COVID-19 related questions to a medical provider. In addition, we found that it was important for families to be contacted seven days per week. Through our conversations, families had the opportunity to make the team aware of what is important to their loved ones who were admitted, especially those who were intubated or too fatigued to speak. Families also appreciated handwritten condolence cards that included contact information for the palliative care team in case they had questions in the wake of their family member's death.

Staff appreciated in person daily rounding of the palliative care team with a focus on just-in-time education tips. Offering scripts for discussing health care proxy, how to discuss code status, and how to facilitate final goodbyes over the phone lowered the angst of primary providers. Many staff members expressed appreciation for palliative care team notes, as the unique style with direct patient and family member quotes helped them get to know the patients and their family dynamics. This allowed them to feel more confident when calling family members with daily updates or to facilitate final phone calls. One important aspect of the note template was inclusion of household screening questions that served as an important data base for contact tracing in households. Finally, knowing palliative care was a 24/7 service gave primary teams who rotated every three days peace of mind, as our team was able to provide continuity of care for families.

What will we do differently if we are asked once again to expand our service and care for adults? Team training will include more tips for talking patients through acute anxiety, including guided imagery and mindfulness strategies. All supportive and bereavement calls will be made through video platforms. Face-to-face contact through video has now become the norm and is much easier to accomplish. Note templates will include social determinants of health screening, as that information proved helpful in connecting vulnerable families to community supports. The bereavement note templates will include evaluations for financial need for funeral planning. Bereavement callers will be equipped with more resources targeted at helping families grieve while socially distant.

While the positive feedback from patients and families has demonstrated that our work has made a difference for them, we can confidently say that opening our doors and hearts to caring for adults during this pandemic has changed us and our practice for the better as well. As pediatricians who practice family-centered care with a focus on shared decision-making, caring for adults requires a daily reminder of their independence and choice. When reaching out to family members, we learned to first obtain the permission of the adult patient and clarify what information can be shared with whom. Health care proxy determination as a patient right is now being promoted to empower our patients 18 years of age and older. In fact, there is currently a quality improvement project underway to raise the rates of health care proxy completion on all patients admitted over 18 years old. We are continuing to normalize advance care planning, starting with asking patients to choose who should speak for them and make decisions on their behalf if they suddenly cannot. Montefiore Medical Center has committed to staying paperless, thus we are working towards the incorporation of eMOLST, an electronic platform for recording Medical Orders for Life Sustaining Treatment, into the practice and policies across our healthcare system. We have engaged community care partners in this journey from rehabilitation centers to subacute care centers and hospices. Finally, self-care practices developed during the surge have stayed in place, as they proved essential to nurturing self-compassion and the wellness of our team.

At CHAM, we have always called ourselves a CHAMily, reflective of the cooperative nature of our work and the camaraderie among colleagues. This “family approach” to COVID-19 has only strengthened the bonds among our staff and faculty. From our family to yours, we hope that our reflections and experiences can help you and your team as you care for adults with COVID-19 and their families. The essence of palliative care does not change based on the age of the patient that we are caring for, as the goal is always to alleviate suffering in all its forms. Our ability and opportunity to rapidly expand our palliative care team to provide support to more patients, families, and colleagues, helped our CHAMily maintain our collective humanity while facing uncertainty and loss. We are sure it will do the same for you.

Helpful Resources

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3. COVID 19 resource hub: <https://www.capc.org/covid-19/>
4. Sesame Street Caring for Each Other: <https://www.sesamestreet.org/caring>
5. Parenting in a Pandemic from the American Academy of Pediatrics: <https://www.healthychildren.org/English/health-issues/conditions/COVID-19/Pages/Parenting-in-a-Pandemic.aspx>

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BOUNDARIES, BURNOUT, AND COVID-19...OH MY!

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A real-life dilemma (patient de-identified for privacy):

Years ago, I was a relatively new nurse practitioner in a specialty practice. I enjoyed the work, the families and especially my preschool age group. These kids facing life-threatening conditions were living their lives and trying to keep as much normalcy as possible. One of these young boys, I shall call Joshua, was fighting not just the disease, but the accompanying side effects of treatment and the assault to his normal life. Within months of his diagnosis, his fifth birthday was near. His mother, a constant presence by his side, approached me in clinic one day and handed me an invitation. With this precious gift, she shared his logic in inviting me, a young nurse practitioner on his team. Josh had chosen me as one of his top five people he wanted at his birthday! She then said the words that any God Fearing, Guilt Ridden Catholic dreads, "You were his third choice; no pressure...". Argghh! No Pressure! I had never socialized with a patient outside of the hospital! But this child clearly wanted me to be at his birthday party at his home! Should I go?

How Do We Define Professional Boundaries?

Risky boundary behaviors or **What Not to Do**:^{1,2}

- Discuss personal issues with a family or patient
- Give out personal cell/phone number or home address
- Prioritize work over family
- Socialize with patients/families³
- Believe that you are the only one who can help the patient
- Show favoritism to a particular patient or family
- Break down emotionally in front of a patient or family (a few tears are OK)
- Allow your own needs (such as ego, emotional, or psychological) to influence your decision-making with the patient

How to avoid boundary violations or **What to Do**:

- Always act in the best interest of the patient
- Reach out to colleagues for help in assessing potential boundary crossings or violations
- Consider repercussions or impact on your team
- Review your hospice/hospital professional boundaries policy

Back to the Case:

Reflecting on the boundary behaviors listed above, I worried that to attend the party it might seem like favoritism. Hmm... What to do? As mentioned in the how to avoid boundary violations list, my intent was to honor this young child's request to attend such an auspicious occasion as the fifth anniversary of his birth. After all, attendance at a patient's memorial or funeral is a mark of respect and support for the child and family. Why would this be any different?

Boundary Violation, Crossing, or Drift?

Would I do this for any other child? I have never said no to an inpatient party for any child. If they asked for me to attend a party outside the hospital, I might consider if I was able to escape from work. I discussed my dilemma with my specialty team and my nursing supervisor. The nature of the crossing was deemed relatively minor given that this particular social activity outside the workplace did not show favoritism since this was the only invitation I had received. All agreed I should go, as this temporary boundary crossing still allowed for a therapeutic relationship with the child and family.

Why are professional boundaries important?

There are many potential outcomes from boundary violations, depending on the severity and context in which they occur. The list below offers a few potential outcomes as reported in the literature. For this article, keep in mind the bi-directional link between boundary violations and burnout. Burnout can lead to boundary violations and vice versa.

Patient outcomes:^{1,2}

- Poor patient outcomes
- Medical errors
- Depersonalization of patients

Provider outcomes:¹

- License suspension or revocation
- Change of field
- Suboptimal care provided

Profession outcomes:^{1,2}

- Diminished workforce—People who are burned out are more than 3x as likely to resign
- Low morale
- Financial toll
 - Absenteeism- 63% increased likelihood to call in sick
 - Job turnover costs—cost for orienting new people
 - Lost productivity

What if I am already feeling crispy, say in a pandemic?

The incidence of burnout is high in the healthcare profession given our repetitive exposure to work-related stressors. The National Academy of Medicine reports that nurses and physicians have a 35 to 54% chance of burnout. Physicians with burnout are five times more likely to leave medicine. Within our population of hospice or palliative care our risk for burnout is even higher (>60%) since we are exposed to emotional distress and physical suffering on a frequent basis.⁴ The pandemic has had an impact on compassion fatigue and burnout. Several studies are measuring the impact of the pandemic on healthcare providers.^{2,5} All studies thus far have concluded that the impact includes benefits and burdens of the pandemic. Stressors are akin to any crisis on the healthcare workforce.⁵

The nature of the pandemic has contributed to the already-present stressors of healthcare by adding another layer of uncertainty, grief, loss, moral distress, and general fear for basic needs such as safety, transportation, caregiving supports.^{5,6} These stressors contribute to an otherwise burdened system. There have been multiple changes that have evolved the current norms of work and personal life. As we adapt to the present norms, more change is coming as we brace for the next surge of COVID-19 patients within the uncertainty of the cold and flu season. And yet, a prevailing feeling of hope accompanies the first wave of vaccinations against this far-reaching, insidious foe.

The rapidity of change has highlighted the need for adaptability and resilience to not only survive, but to thrive in the face of an historic pandemic. With the advent of the coronavirus vaccine, herd immunity and eventual eradication are possible. For palliative care clinicians, positive changes attributed to the pandemic include more focus on work/life integration and heightened sense of what matters most.⁵ Potential professional benefits include increased awareness of professional purpose and recognition of professional opportunities for growth.⁵

What type of strategies can organizations employ to protect their employees from work-related stress and burnout in a pandemic?

Ask your people! What do you need to help manage the stress of the job?

Here are a few suggestions⁷:

- Adequate staffing as able
- Acknowledge staff accomplishments
- Involve staff in decision making
- Recognition of each staff member as an important member of the team and organization
- Prioritization of safe work conditions
- Transparent leadership to include information on the safety and security of job positions
- Promotion of healthy work relationships

What can we do to promote resiliency in ourselves?⁸

- Prioritize self-care
- Sleep, eat, exercise
- Cultivate stress management techniques such as relaxation breathing, mindfulness
- Express gratitude
- Celebrate successes
- Cultivate your community—Who’s in *your* corner?

Case Wrap-up: So, what did I do?

I joined in the birthday celebration. I even joined in the kids’ games—especially the moon walk! This celebration seemed supportive of Joshua, his family, and me as a health care provider.

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CREATIVITY DURING COVID-19 IN HONORING A CHILD WHO HAS DIED

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During COVID-19 many people are working from home, school is remote, and many concerts and sporting events are cancelled. However, caring for children at the end of life has changed very little. Coastal Kids Home Care palliative and end-of-life services offer families caring for terminal children the opportunity to die in the comfort and dignity of their own home. While the period of time preceding and immediately after the death of a child is typically very inward looking, following a child's death, families began to look outward for support from family, friends, and spiritual communities.

Restrictions around the pandemic have dramatically altered all communal gatherings, and there is no exception for bereaved families. In this context, social workers and counselors supporting families coping with the loss of a child are challenged to help grieving parents shift their family, religious, or cultural expectations of gathering to other activities that will meet their need for emotional connection and memorializing of their child. At Coastal Kids Home Care, our pediatric palliative care team begins working with parents prior to their child's death to explore practical and creative options to help them process and express their grief.

The emotional and physical well-being of parents and other family members during bereavement is paramount. Beginning a conversation with each parent about "what they need most when they feel worst" and identifying individuals in their family, social, or spiritual communities who meet some of these needs is a critical step. Connecting with these individuals must now include social distancing and mask wearing when together. Connection may also include use of technology including phone applications, social media, and computer video chatting. Encouraging parents to connect with a physician to address the physical symptoms of grief like insomnia or loss of appetite is also important. Further, identifying activities, such as walking outdoors or talking to a close friend, which have helped them cope with the many losses that have occurred on the path to their child's death, can encourage the creation of comforting rituals going forward.

Funerals or other ceremonies are also important rituals for the living. They offer bereaved parents, siblings, and other family members a way to acknowledge the reality of death, express grief, and find meaning in their child's life. While most faith communities have developed ways to conduct traditional ceremonies during COVID-19, gatherings are often limited in size and location. Thus, facilitating broader communal expressions of grief has required greater ingenuity. In these circumstances, families are relying on socially-distanced connection, technology, and nature to celebrate with loved ones.

- Some families are drawing upon the life of their child for inspiration. One mother printed and framed her daughter's art and shared it with family members, close friends, teachers, and other professionals. Another young boy suggested that everyone who loved his sister release a balloon in their favorite color, all at the same time, wherever they are sheltering in place.
- Technology is being employed in unique ways. One family live-streamed 24 hours of chanting at their child's bedside. In this customary tradition of Vietnamese Buddhists, dozens of members of their community took turns chanting to ensure the child was surrounded by messages of peace and happiness. Other families have included friends and families via Zoom at funerals and burials; although this is an imperfect solution, it is one way to include distant relatives during these unusual times.
- There is an abundance of room for creativity in nature as well. Two young parents invited their friends to a favorite beach. They all spread out and tossed a red rose into the ocean while sharing their wishes for the young girl who had died. Words like "peace," "freedom," and "milkshakes" rang out amidst the pounding of the waves.

After a child's death, many parents want to carry their memory forward—to hear and say their name, recognize their favorite things, and pay tribute to their unique personality. Now, more than ever before, legacy-making has become a vital way for parents to keep their child in the forefront of their lives and those of others. One mother, whose daughter died of cancer in March, began a food drive in her honor to assist people who had become food insecure due to COVID-19. Another family who lost a medically fragile infant this summer is preparing a simple altar for Dia de Los Angelitos. Legacies reflect the individuality of the child and what they cared about. It can even be as simple as thinking about the deceased regularly or talking out loud to them.

COVID-19 has also altered how bereavement counseling is offered for families coping with loss. Losing a child is devastating and many parents and siblings experience a complex range of emotions. During this time of increased social isolation for our whole community, access to bereavement counseling for parents and siblings is even more critical. Coastal Kids Home Care finds that for those families to whom our counselors have a strong connection prior to a child's death, the transition to bereavement counseling is smoother. Telehealth therapy has proven an effective way to reach many individuals. Others prefer in-person counseling which can safely be done with masks in outdoor spaces or socially distanced indoors. At the same time, faith-communities have important resources to support grieving families. They, too, have adapted to

the current conditions offering online grief support groups or smaller socially-distanced meetings.

The current pandemic is inspiring us to create new traditions and cope in new ways that will support us long after we have returned to a world in which we can gather. Until then, creativity is the key to honoring and celebrating a child who has died.

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VIRTUAL MEMORIALIZATION EVENTS IN THE ERA OF COVID-19

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March 23, 2020...this was the day Governor Jay Inslee issued the stay-at-home order for residents of the state of Washington due to the rising cases of COVID-19. Two weeks later was our first meeting to plan for our hospital's annual memorial service for grieving families. This feels like a lifetime ago and yet we still feel like we are in our infancy in creating meaningful support services for grieving families. The Journey Program is the bereavement program for Seattle Children's Hospital, and since our founding in 1989, we have always provided an in-person Annual Memorial Service for families in our region to honor the lives of their children. So, when our multidisciplinary team, comprised of child life specialists, music therapists, social workers, chaplains, audio-visual experts, and community volunteers, met on April 3, 2020, we had to decide rather quickly what we needed to do. We discussed 4 options:

1. Continue to plan for an in-person service held in the hospital's auditorium since the original lockdown order was just for a few weeks
2. Cancel the service for this year
3. Reschedule the service to a later date in 2020 when the lockdown order would be lifted and social distancing would no longer be necessary
4. Plan for a virtual and asynchronous service.

In all honesty, we truly believed that Option #1 was the only choice. I reflect on this naïve belief with humor, compassion, and, certainly, grief on how much we now have strayed from Option #1. After much discussion and several reality checks later, we had to settle on Option #4. But once we settled on this option and everyone was in agreement, it actually felt liberating to move forward and be creative...but not reckless or overly creative because we knew how important this service was for many families. Slight derivations from certain expectations could exacerbate tender feelings. We talked openly about the elements of the service that were sacred and meaningful to families, based on the many years of feedback and observations. And what we settled on was to accept, and, finally, appreciate that the memorial service structure that has been designed, created, edited, and shaped over the years by families' grief was actually the sacred element. The structure had to remain intact, and all we had to do was translate this structure virtually and asynchronously.

We chose to deliver the service asynchronously from the lens of equity and inclusion. A significant percentage of families do not have stable wireless access points, in addition, many families do not own devices that can process live data. The asynchronous platform also gave us the opportunity to be inclusive and finally create a service for Spanish-speaking grieving

families, versus using an interpreter or Spanish captioning within the recorded service. We now had to plan two services before publishing the service on June 7, 2020. This meant we did not have a lot of time to work with, if we committed to keeping the integrity of the service structure, which is outlined below:

1. Sharing of the Memorial Activity that families returned to us: drawings and photos from the siblings (we sent materials to all the families via mail a month before the service)
2. Gathering music by music therapists
3. Introduction by our spiritual care department
4. Welcome by our hospital leadership
5. Various patient music interludes created and written by patients who have died
6. Responsive opening prayer by bereaved parents
7. Parent's Grief Journey by bereaved parents
8. Physician's Grief Journey by children's physician
9. Journey Program Reflections and Prayer of Dedication by a grief counselor
10. Reading of "Calling Out of the Names," by Washington State Poet Laureate Elizabeth Austen
11. Moment of silent reflection for their child's name to be shared and spoken
12. Candle lighting ceremony and remembering
13. Singing of song "Sending You Light" by our music therapists
14. Playing of the sibling song, "I Remember You," introduced by the music therapist
15. Closing sentiments by our spiritual care department
16. Closing music by our music therapists

We worked closely with the audio-visual department, who fully understood the purpose and sanctity of the service and with whom we had built a close working relationship over the years. After receiving confirmation from all of the invited speakers, we then reserved the auditorium to stage the background with familiar visual cues, such as, a flower arrangement, the candles, and the beloved Memorial Books which hold the names of the children. We also created a two-week schedule for each speaker to be recorded in the auditorium. Because of the hospital's COVID-19 policies, visitors and non-Children's employees were not permitted inside the hospital. We then introduced the audio-visual department to all of the speakers who needed to record their part in their home. They were given guidance on lighting and the ideal location to film. The AV department was also responsible for editing and splicing all the recordings with carefully chosen images of familiar and meaningful scenery from the state of Washington and the Seattle area. The parent speakers also sent photographs of their children. These images were shown during their part of the program. Additionally, the music therapist sent a power point with the lyrics to the sibling song "I Remember You," which was presented with the audio.

We sent two communications to families: one was a save-the-date notice that explained how the service will still be held but not in-person. We then sent an invitation a couple of weeks later with a request to RSVP. Those who replied with an RSVP were mailed and emailed the links to view the videos of the service. We used the Seattle Children's private Vimeo account and published the videos for viewing on the scheduled date and time. Prior to publication on Vimeo, we requested the AV department to send a video draft three weeks prior to June 7, so that we all had a chance to view the service to talk about errors or revisions and any potential re-recordings of segments. Thankfully, we only had minor revisions and edits. We had some last-minute changes, but because we gave plenty of time for revisions before publication, we were able to respond accordingly.

We did not know what to expect as feedback from the community, and we were unsure how much of the sacredness and meaning were going to be conveyed. We were surprised by the overwhelming positive responses from families. We also were relieved to see that the number of views tripled the number of our in-person attendance. It was quadrupled for our Spanish-speaking families. Since we are a regional hospital that covers four states, we attributed the increase in "attendance," which were the views, to accessibility. Families who were not able to travel from different states and from different parts of Washington were now able to "attend" virtually and access not just a service to honor their child but to feel the collective grief of all the other families who logged on at the same time from all parts of the region. It was especially meaningful for our more marginalized grieving families, such as the Spanish-speaking families who now were able to participate in a culturally responsive and linguistically congruent service. Many families shared that it was special to view the service in their home, surrounded by the memories and belongings of their beloved child. Some families also shared how much more able they were to fully cry and be emotional because they were not in a public space. Families also shared that they might not have come, if it was an in-person service, because coming back to the hospital was re-traumatizing.

We learned many things from this experience: from the technical aspects of asynchronous recordings to letting go of outcomes over which we have no control. We learned the importance of inter-departmental collaboration and trust, and the value of open and frequent communication since we were not able to meet in-person as a planning committee. We learned the value of simplicity. We did not have to re-invent and re-create a memorial service. We learned that we already had everything we needed to move forward. Most importantly, we learned about equity and access and the importance of inclusion. In the end, we let go of Option #1 and learned to embrace and accept Option #4.

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FUNERALS AND MEMORIALIZATION IN THE TIME OF COVID

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As I write this, we are approaching the end of a year that has, for me at least, felt much longer than that! There has been so much change, stress, trauma, and grief that each of us have had to endure. A global pandemic, natural disasters, civil unrest, political discord (just to name a few!)...we've all been impacted in some way. For the families we work with, they have been dealt an added layer of trauma added to an already overflowing plate. For those parents that have had a child die this year, this blow seems especially cruel and devastating amid everything else that is going on.

Having to say goodbye to a child is an incredibly difficult task for parents. This out-of-order death is traumatic, no matter how the child died or what their age was. It violates the rules of life and shatters the presumptive world view that parents do not bury their children. It's *supposed to* be the other way around. A parent's main role is to protect their child; when that child dies, there can be a lot of guilt and shame that they somehow "failed," despite all the evidence in the world that there was nothing the parent could have done to change the outcome. It takes time for the heart to catch up with what the head understands as truth. Bereaved parents are *still* parents to their now-deceased child and our job is to help them find their footing and navigate this changed role.

After a child has died, one of the first tasks is for the family to plan that child's end-of-life rituals and the disposition of the child's body. Now more than ever we see the importance and significance of these rituals. Unfortunately, because of this global pandemic, some of these rituals are being restricted in many ways. But that doesn't change the fact that these rituals are incredibly helpful for us as we begin to grieve a significant loss. One purpose of end-of-life rituals is to mark the transition from the life as we knew it to the new life we have to live after our beloved has died. These rituals also provide a container for the physical and emotional expression of grief and gives those grieving practical tasks to do to honor their loved one as they plan and prepare for them. These rituals also allow others to support the family, which is needed now more than ever, during these times of physical distancing. Rituals give us opportunities to reflect on our loved one and the impact they had on our lives. When these rituals can't happen, the grief is still there, waiting. The ongoing, lifelong grief is put in a kind of holding pattern that prolongs that initial sharp wave of grief indefinitely. As John Greene said, "The thing about pain is, it demands to be felt."

Let's talk a little more about grief rituals. We also need to recognize the importance of personal and private ongoing rituals for grief. So, you can encourage families to find the things that help

them feel close to the love they have for their special person. That love is always there, no matter how hard the rest of the world is trying to get those grieving to leave that behind. We know that the old adage of severing the ties we have with those that have died is **not adaptive** to the grieving process. What is adaptive is continuing that bond with the person who died, just in a different way! Our loved one might not be physically present in our lives, but they will always be a part of who we are and that is something to always hang on to.

Just as our families have dealt with restrictions at hospitals during this pandemic, there may also be different restrictions at any given time when it comes to funerals and funeral services. From limitations on the number of people in attendance, to the length of time a service can be, all these restrictions are in an effort to keep everyone safe and slow the spread of this virus. For our families, when they can't have the funeral they thought they would be able to have, that is another layer of grief. Layer upon layer of grief can lead to a very traumatic grief experience. The key we must remember in all of this is that *we can (and must) find options within the restrictions!* It is NOT "all or nothing." We can still do *something* and that *something* is better than *nothing* when it comes to a grieving heart. Maybe that smaller something is done now and a larger something is done later, perhaps on a special day, like a birthday or the one-year anniversary when it is safer for more people to gather. As someone who is helping the family, be their advocate. Find out the current policies and procedures of the funeral homes in your area. Then, help the family come up with creative ways they can honor their child (both now and in the future) within these boundaries. Continue to support them as they begin to live this new life without their child. By doing all of the things you already know how to do, just perhaps reframed in new and innovative ways, you are helping to mitigate some of the impacts that all of this trauma has on a family.

Considerations for funeral planning:

If it is an option, encourage the family to make arrangements for the funeral or memorial service **before** the child dies. This can help prepare the family for what the process will be like when the child does die and create the opportunity for the child to be a part of the process. An example of this was with a family we served whose five-year-old son, Garrett, was dying of cancer. They asked him what he wanted for his funeral and he promptly told them that he wanted an "Asgardian burial just like Thor's mommy" and wanted "bounce houses and super heroes" at his celebration of life. It was the perfect send-off to a little boy with so much spunk and zest for life.

(For more ideas on incorporating terminally ill children in planning their own wishes, visit: [FiveWishes.org](https://www.fivewishes.org) - My Wishes and Voicing My Choices workbooks)

Considerations for bringing the child's body into the funeral home's care:

- By law, the funeral home has a certain amount of time to come to receive someone who has died into their care. Be sure to explain what will start to happen to the body after

death, but be sure to give the family time to spend with their child's body. Inquire with a local funeral home to find out what the laws are in your state.

- Make the removal process a ritual! Light a candle, read a short poem, play soft music.
- Involve the parents. A parent can, if they would like, carry their child out to the vehicle that will transport the child's body to the funeral home or the parent can help the funeral director as they do this.
 - This is one of the hardest things for funeral directors to have to do. Taking a child from their parents is so intimate and sacred, so if it can be a collaborative effort it can make the process easier for everyone.
 - If the family was able to pre-plan, this part is a lot easier because they are familiar with the people who are taking their child's body into their care.
- Many parents want to know where their child's body is at all times. Be sure to talk about the process so the family knows where the child's body will be transported to, locations of the funeral home, crematory, etc.

Considerations for the funeral service:

- Make the funeral service really speak to who the child was. It is not a 'one size fits all' when planning a funeral, especially for a child. Think about what made the child unique and how you can use those aspects to personalize their services.
 - Favorites: colors, characters, movies, songs, sports teams, toys, etc.
 - Any other special things the child enjoyed or participated in
 - Consider take-home mementos for guests (i.e. a bowl of their favorite candy)
- If you have to limit the number of people in attendance, see if there is an opportunity to livestream the services. Many funeral homes now have this capability and if they don't, you can utilize Zoom, Facebook live, etc. to help broadcast to family and friends near and far. People can leave comments to let the family know they are "with" them. Families could consider having a "Zoom Reception" afterwards with close family and friends. Encourage all attending to make the child's favorite food and eat it together while sharing stories.
- If the child's body will be buried at a cemetery, consider having a "Realtor's box" at the graveside containing memorial programs for visitors to take. Another idea is to have visitors leave flowers or mementos at the graveside (or at the family's home).
 - One family whose son died had a private graveside service with just the family; the child's classmates were invited to decorate a rock to leave at the graveside for the family to receive later.
 - Another family put a tree on their front porch on which people could leave decorated ornaments in honor of their son that recently died.
What beautiful ways for these families to see they weren't alone!

- Don't forget about the other kids! Siblings, friends, and classmates of the child who died **can and should be involved!**

Examples:

- Have siblings help pick out the clothes the child's body will be in for services, the casket color, other mementos to go in the casket or that will get cremated with the child's body.
- If they cannot attend the service, watch the livestream of the service
- Set a time for all the kids to go outside and blow bubbles or let go of balloons in honor of the child that died.
- Write letters and/or draw pictures to be placed in the casket, cremated with the child, or given to the family.
- If you were close to the family, consider volunteering to be a "buddy" for the siblings during the services. You can help them understand the rituals being performed and give the space and time for the parents to attend to their own grief during the services.
- For more ideas, check out our handout called "Kids & Funerals: During a Global Pandemic."

For more information on how to talk to kids and include them in end-of-life rituals, see the National Alliance for Grieving Children's GriefTalk Resource Guide, "Talking about End of Life Memorials and Rituals" at childrengrieve.org.

I hope that this gives you a springboard for some ways families can honor their child who has died during a global pandemic. If you would like more information, please contact me at Hamilton's Academy of Grief & Loss, or visit our website: hamiltonsfuneralhome.com.

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COVID-19 Pandemic Restrictions and the Use of Technology for Pediatric Palliative Care in the Acute Care Setting. Bettini, Elizabeth A. Journal of Hospice & Palliative Nursing. 2020 (December);22(6):432-434

Summary: This is a helpful summary, including a case presentation, of telehealth innovation based on necessity. COVID-19 threw a metaphorical monkey wrench into the logistics of advance care planning, patient and family support, and care of the child/family at end of life because of the restrictions of minimizing physical contact. This pediatric palliative care (PPC) team adapted some of the telehealth outpatient and home hospice strategies to the inpatient setting. They supported and educated hospital-based providers, many of whom had limited expertise in using telehealth, in communicating with their patient's family. They were successful in using telehealth over multiple sessions to successfully develop an advance care plan including goals of care.

Who might find this information useful? Inpatient health care providers and others restricted by physical distancing will learn from this example of using telehealth to have structured goals of care discussions.

What is special about this article? Although brief and case based, this article outlines the steps to develop a very helpful process based on telehealth to ensure excellent palliative and end-of-life care despite the COVID-19 necessitated barrier of physical distancing. Semi-structured conversations over a period of time included prognosis, goals of care, helpful resources, and decisional support. The team was able to provide psychosocial support and suggestions about legacy-making activities. The PPC team found that it was very helpful to be able to "read" body language as they had difficult conversations via telehealth. They were able to provide support not only to the parents but also to distant family members as the child was extubated and died. Although this extubation occurred in the hospital, support of the family would have been even more difficult had the child died at home without the presence of the PPC team via telehealth. The authors specify a number of telehealth systems that are adaptable. Not all of them are HIPAA compliant! Barriers to using telehealth are also outlined. Not all families are technologically savvy and some do not have access to the internet. Families whose first language is not English may find this process difficult and need to be supported by an interpreter.

Where and how can I apply this information? In addition to the inpatient care of a seriously ill child during the COVID-19 pandemic, this process can be extrapolated to other situations. Consider the case of an ill parent or family member who cannot visit the child in the hospital, or a far distant relative. Because of COVID-induced increased experience with telehealth, the technology may become much more common in the outpatient setting, including in rural areas and other situations where access to care is difficult.

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ITEMS OF INTEREST

In each issue of our Pediatric E-journal, we offer additional items of interest.

1. NHPCO Palliative Care Online Resources:

NHPCO has a variety of pediatric hospice and palliative care resources available at www.nhpc.org/pediatrics. Also, more palliative care resources are available at www.nhpc.org/palliativecare, including:

- Community–Based Palliative Care
- Legal and Regulatory Resources
- Webinars and Courses
- Plus, more for NHPCO members

Palliative Care Programs and Professionals

Founded in 1978, National Hospice and Palliative Care Organization (NHPCO) is the world's largest and most innovative national membership organization devoted exclusively to promoting access to hospice and palliative care and to maintaining quality care for persons facing the end of life and their families. **Join NHPCO Today!**

[Individual Palliative Care Membership](#)

[Palliative Care Group Application](#) - Save by registering your entire team

2. Pediatric Hospice and Palliative Care Resources:

- **CaringInfo**, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. www.caringinfo.org
 - *When Your Child is in Pain*
 - *Talking with Your Child About His or Her Illness*
 - *Talking to Your Child's Doctor: When Your Child Has a Serious Illness*
 - *When a Child Dies: A Guide for Family and Friends*
 - *Helping Children Cope with the Loss of a Loved One*
- **NHPCO's Palliative Care Resource Series** includes pediatric palliative resources such as:
 - *Communication Between Parents and Health Care Professionals Enhances Satisfaction Among Parents of the Children with Severe Spinal Muscular Atrophy*
 - *Consideration for Complex Pediatric Palliative Care Discharges*
 - *'Who You Gonna Call?' Men with Duchenne Muscular Dystrophy Discuss End-of-life Planning*
 - *Songs of the Dying: The Case for Music Therapy in Pediatric Palliative and Hospice Care*

- *Nonpharmacological Pain Management for Children*
- *Sibling Grief*
- *Pediatric Pain Management Strategies*
- *Communicating with a Child Experiencing the Death of a Loved One: Developmental Considerations*

3. Trends in Pediatric Palliative Care Research

Every month, PedPalASCNET collects new pediatric palliative care research. For past lists visit [their blog](#), [browse in their library](#), or join the [Zotero group](#).

[View the New Citation List in their Library](#)

4. Pediatric Hospice and Palliative Care Training:

- **[Upcoming Webinars](#) provided by the Pediatric Care Coalition:**
 - February 16: Together in the Sandbox: Palliative Care and Complex Care Partnerships in the Medical Neighborhood
 - Mar 16: Using POLST/MOLST to Engage in Meaningful Conversations in Pediatric Palliative Care
 - Apr 20: Big Pharma – Little People

5. Pediatric Resource on Medication Coverage:

In an effort to standardize the medication coverage process for children receiving concurrent care, the National Hospice and Palliative Care Organization (NHPCO) Pediatric Advisory Council developed a new resource for providers titled [Determination of Hospice Medication Coverage in CHILDREN](#).

6. Subjects and Contributors for Future Issues of This E-Journal.

We are currently discussing topics such as lessons learned from COVID-19, telehealth & pediatric hospice/palliative care, and inequities or disparities in pediatric hospice/palliative care for issues in 2021. If you have any thoughts about these or other topics, contributors, or future issues, please contact Christy at christytork@gmail.com or Suzanne Toce at tocess@gmail.com.

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