MEDIA, TECHNOLOGY, AND COMMUNICATIONS

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Issue Topic: Media, Technology, and Communications

Welcome to the 76th issue of our Pediatric e-Journal. Our focus in this issue is on subjects involving media, technology, and communication as they are related to pediatric hospice and palliative care.

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 Melissa Hunt. Chuck Corr is our Senior Editor. Archived issues of this publication are available on the NHPCO website.

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 open to suggestions for the four issues that will follow in 2025. Before that, our plan is to address issues related to home care and community care in Issue #77. If you have any thoughts about these topics or other subjects for future issues in 2025 and/or potential contributors (including yourself?), please contact Christy Torkildson at Christy.Torkildson@gcu.edu or Melissa Hunt at Melissa.Hunt@optum.com.

Views expressed in this and other issues of the Pediatric e-Journal are exclusively those of the authors and do not necessarily reflect the views of the Pediatric e-Journal Workgroup, the NHPCO Pediatric Council, or the National Hospice and Palliative Care Organization.

Produced by the Pediatric e-Journal Workgroup

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A mother of a child with medical complexity describes the diagnosis, birth, short life, and death of her daughter. Along the way, she reports that, "The social media allowed me to feel hope then gave me a sense of purpose after her passing." And she adds, "I'll be forever grateful for the possibilities that it opens up, the connections I made, and the hope that it gave me."

In this article, the mother of a child with medical complications poses the question: "When is social media more than just endless scrolling and a waste of time?" After describing her journey with her child, her answer is: "When you make amazing connections with families all over the world, connected by such a thin thread, all because of a devastating, life-changing diagnosis. Social media has bridged the gap that physical distance creates. Good can come from bad and there is joy in the journey. With social media, parents do not have to walk the journey alone."

This article is a reflection by an experienced pediatric chaplain on what it is like when a child dies. He observes that each such experience is unique, but it is always sad. Sometimes it is chaotic, terrible, and unexpected. But sometimes it is anticipated and peaceful. Sometimes professionals in pediatric palliative and hospice care can quietly and thoughtfully help to prepare and support the family. He concludes in the following way: "For those who do this delicate and gentle and beautiful and courageous work of caring for children, I hope you have the resources you need to do it in the ways that you know it should be done. In the face of these stories always being sad, I hope you have the personal bandwidth necessary to do it well while also keeping yourself healthy and whole. With you, I hope for a day where there is not a threat of a child dying. And until that day, I hope we are all able to continue to work to make those moments as peaceful as possible."

Scott Newport has made many contributions to this Pediatric e-Journal. In them, he has described living with a son with medical complexity, the death of Evan, and Scott's subsequent work as a volunteer offering support to families in similar situations both before and after the deaths of their children. In this short essay, he describes a new initiative in which he invites those he interviews to imagine themselves as an inanimate object and then to paint a picture of what they have imagined. Attached are photos of those who interacted with Scott in this way and of what they painted.

The Crucial Role of the Medical Interpreter: Focus on Pediatric Palliative Care Encounters **p. 9**

Yaira Demera, Certified Medical Interpreter and Translator

This article describes the work of medical interpreters in a children's hospital in New Orleans. The author offers suggestions to help children and family members with limited English proficiency in understanding the care they are receiving. Attention is focused on "how culture impacts the way an illness is viewed can lead to misunderstandings and communication problems during family meetings." The author points out the medical interpreter's roles as the conduit in converting dialogue into the target language, as a cultural broker in helping to ease distrust and changing interpersonal relationships with the provider team, and as "a catalyst for change with the ambition to promote inclusivity and a collaborative environment for providers and patients alike."

Communicating Wishes in Serious Illness: Based on the National POLST (Physician Orders for Life-Sustaining Treatment) Form **p. 12**

Judy Zeringue, MAPL, BSN, RN, CPLC, CHPPN

Documents designed to serve as portable medical orders through which individuals can voluntarily express their wishes for specific forms of treatment in specific situations have become more prominent in health care in recent years. Because they are authorized by state legislation, they are referred to by different names and acronyms in different states. This article explains the general form of such documents and shows how they can be made applicable to pediatric situations.

Using Digital Resources to Support and Educate Caregivers and Clinicians **p. 15**

Chrissy Salley, Ph.D.

In this article, the author explains how her early training as a pediatric psychologist focused on preparing her for face-to-face interventions with parents and other caregivers of children with serious illness. She then acknowledges that, "the reality is that all psychosocial providers are stretched thin…[and explains that] Focus is often on acute 'problems,' meaning other emotional needs get tabled. There just isn't enough time or resources to go around." She then offers how her work at Courageous Parents Network (CPN) has shown her that "there are caregiver needs that can be met at low costs with big impact…What I have come to understand is that not only can this be done well, it actually fills gaps in the care of caregivers. Importantly, it is a good compliment to, and can enhance the support delivered by, a clinician." The article concludes by describing the characteristics of digital resources available from CPN.

Digital Platforms and Social Media in Pediatric Palliative and Hospice Care: The Positives and the Pitfalls **p. 17**

Ann Fitzsimons, BS, MBA, and Matthew Misner, DO, MS, MAPS

"This article will explore some of the benefits and the "bad parts" of social media from different perspectives—parents, the public and providers—in an effort to help present some considerations of when, and how it can and should be used, and when it needs to be reined in or ignored altogether." In this article, several case examples are explored from both the perspective of parents and hospice providers to lead to the following summary: "In conclusion, it is clear that while parents' of medically complex children may benefit from their participation in social media, other online support groups, and the internet in general, this clearly needs to be balanced against: (1) the backdrop of public backlash they could face when posting, (2) the ethical concerns about the child's privacy and his/her ability to consent to the sharing of information and posting of pictures, (3) the misinformation and unvalidated or untested information they can be exposed to which could pose harm to their child, (4) the amount of time spent on these media vs. with their medically complex child or other children in the family, and (5) the issues and dilemmas that may be caused if there is communication with the child's providers outside of the professional's boundaries, among others."

When a Parent Loses a Child, There Are No Words **p. 23**

Sean M. Daley, PhD, MA

The author of this article is both a professor of applied cultural anthropology and indigenous studies, and a bereaved parent. Here he reflects on the lack of a widely-accepted, specific term in the English language for "bereaved parent" by contrast with "widow" for a bereaved spouse or "orphan" for a bereaved child. He explores specific terms in various languages, the word "vilomah" (a term from Sanskrit that has been proposed for use by English speakers), and observes that if "the loss of a child fundamentally changes a parent's identity" what are the implications for parents who only had one child and how should one respond to queries about one's children if one has both a living child and a deceased child. His conclusion asks if we need a new word or perhaps "a shift or reframing of the idea of what it is to be a parent is what is needed."

Pediatric Palliative Care: Why We Should Talk about It **p. 26**

Christy Torkildson, PhD, RN, PHN, FPCN, HEC-C, and Betsy Hawley, MA

This article reviews "recent work highlighting the critical importance of advocating for pediatric palliative and hospice care services. We will briefly compare palliative and hospice care for pediatrics and aim to demonstrate the growing need for enhanced communication to address the challenges in accessing these services." Three examples from recent research are examined to demonstrate "the critical need for increased access to pediatric palliative care and hospice services."

How Social Media Gave Me Hope

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In 2019 I was 20 weeks pregnant with my daughter Lily. My husband and I were extremely excited to do our anatomy scan and see how our baby was progressing. We had dreamed of this moment for over a year after losing our first baby to an early loss. I never imagined walking out of that appointment being handed a soon-to-be-confirmed diagnosis of Trisomy 18. Then I did exactly what I knew I shouldn't do, I googled it. I was immediately presented with grim statistics that sent a wave of fear and grief through me. Not knowing exactly what our future held shattered me. I cried more tears than I can remember as we came up with the courage to move forward.

After researching the internet, I still felt so lonesome in my experience. Reading medical statistics alone wasn't providing the full picture of what lay ahead. I turned to social media in hopes of finding others who had walked this path before. I searched the hashtag #trisomy18 and it opened up a whole new avenue of information. Real life experiences and perspectives that would forever change my life.

I was connected with stories of families who had children living with Trisomy 18, parents with angel babies, and woman who were currently pregnant and working through the same diagnosis. Reading through all of their posts gave me a new found sense of hope. It gave me community. Being able to reach out to other parents who just got it. No need to explain anything. When I read posts by other trisomy parents on their experiences, happy and sad, it was like their words were taken straight from my head. I was more at ease with our journey. That community carried me thru some of my darkest days. I navigated the remaining 18 weeks of my pregnancy filled with hope that I would make the right decisions for our daughter. There were so many options presented to us in determining care for Lily. Seeing others have to make these impossible decisions as well and sharing why they made these choices helped to guide us down a path that felt right for our family. It helped us advocate for our child in a sometimes cruel medical system.

On January 4th, 2020 Lily Ann Outman was born sleeping into this world. The most perfect little girl. Her passing crushed me in ways I didn't know possible. Up until this point I had been private about her diagnosis. Partly for my own sanity. Living in a small town and working in the service industry I just couldn't bear the heaviness of talking about the what if's my entire pregnancy. I just wanted to cherish every moment I could with her. Once she passed, I didn't know how to mother a child that was not in my arms, but I had so much love for her aching to be shared with the world. I decided to share her story on social media. It was part therapy, part awareness. I hoped that providing our story would help me and then in turn help other parents know that they would make it through. Just like other parents had done for me.

The social media that allowed me to feel hope then gave me a sense of purpose after her passing. Sharing our experience on social media allowed me to be a supportive ear for new parents on this path. Be a champion and supporter of other angel babies and living children in our community. It has given purpose to Lily's short life and made me realize the impact that parents sharing their most vulnerable moments can have on others. Every like, heart, and comment helps support other parents through these times. In today's day and age, social media can feel overwhelming and all-consuming in some ways. But for reasons like ours, I'll be forever grateful for the possibilities that it opens up, the connections I made, and the hope that it gave me.

Social Media for Support and Connection

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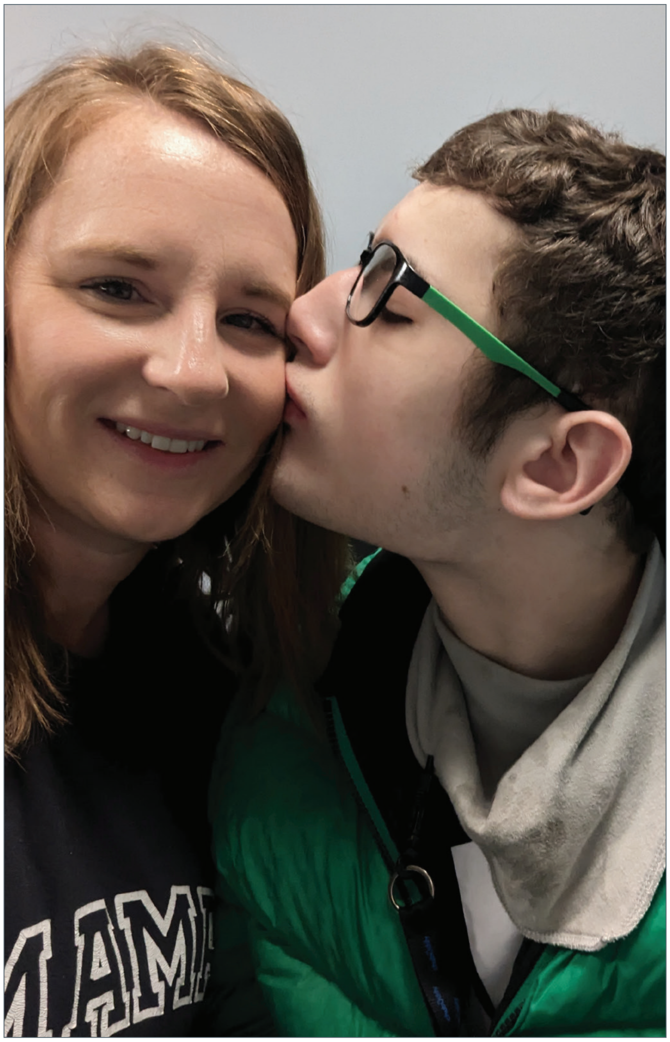
When is social media more than just a platform to engage in entertainment and a time-waster? For me, it is way more than that. It helped me to feel like I wasn't alone. When my son Jackson was diagnosed with Infantile Spasms in 2011, I turned to social media for support and connection. Who could I talk to that would understand what I was going through, and help me navigate this devastating disease? One of the first connections I made was to a mom living in Ohio, whose son was just a few years older than mine. She had posted her personal blog link on a forum for Infantile Spasms, and as I read post after post, I realized our stories were so very similar. This comforted me in a way I can't explain…"so maybe I'm not the only one out there," I thought. I reached out to her by email and we started emailing back and forth. Pretty quickly we were talking on the phone and the support she provided me at that time was so encouraging. Although we have never met in person, social media was a way for us to connect with each other when distance would have made it impossible.

After this initial interaction, I turned to social media to find a community of support. When Jackson was diagnosed with Lennox-Gastaut Syndrome in 2012, it was another pretty devastating blow. But I was able to find the LGS Foundation Online. Prior to the diagnosis, my husband and I had seen groups of LGS families at the National Walk for Epilepsy and I had silently said to myself, "I'm glad I'm not in that group." Very shortly after thinking that, there we were!! Again, feeling lonely and isolated I turned to social media to get connected further. Looking for LGS-specific pamphlets to distribute at a fundraiser we were planning, I reached out to the ICE Epilepsy organization. They didn't have pamphlets for LGS specifically but connected me with the President of the LGS Foundation at that time. I told her I was hosting a fundraiser and wanted to spread awareness about LGS and I was also looking for support groups in Northern VA. In Aug 2012, there were no formally organized support groups. Pretty quickly I jumped, with two feet in, and was excited about spreading awareness and raising money. The next year my husband and I attended our first LGS Family Conference and so much changed for us after attending. We had the opportunity to meet other families and their LGS loved ones, on the same journey. 2013 was the beginning of some beautiful and enriching friendships. And even though we were only seeing each other every two years at conferences, we were staying in touch, digitally connected in many ways.

Prior to Jackson's LGS diagnosis, I had created a Facebook page for him. So many people had no idea what struggles we were going through. This page has been a way to quickly ask for prayers, to show what daily life is like for Jackson, and to spread awareness.

A few years later, I created an Instagram page. I have received countless messages from Moms who somehow stumbled across Jackson's page. They saw their child in the same ways that I was sharing Jackson and there was a connection between us. In this instance, these connections made me feel less isolated.

In March of 2019, a mom emailed me to say that she had been following Jackson's account on Instagram and hesitated to reach out until she finally did in July 2019. Her son's story was eerily identical to Jackson's. Like us, she and her husband were devastated by the news of this life-changing LGS diagnosis. The stages of grief hit all of us



in different ways. When this mom started to get past the denial of the situation, she was looking for someone that could relate. I'm so glad that she found me! I have been so blessed to have her friendship and life experience. To quote her, "I'm not sure if anyone has told you that Jackson's page has made a difference in their lives, but it sure has ours. And your entire family is an inspiration to us." From this point on we have stayed connected, have had the chance to meet at multiple conferences and our friendship has been so special.

Jackson was inpatient at Fairfax Hospital for one week in Nov 2023. During that scary time, I had been keeping his Facebook page updated every day. One evening at 11:00pm while I was passing the time in the hospital, I was reading the comments on one of the Facebook posts I had created. A mom had commented with a photo of her snuggling her little boy in a hospital room. We started to privately message each other and found out that we were in the SAME hospital, on the SAME floor, three rooms apart. We were able to slip out of our rooms for a brief moment and instantly hugged. Even though we had just met, we had that bond. You see, a few months prior, she had been researching a diagnosis that her son was thought to have and Jackson's page popped up. Who would have imagined that a connection in cyberspace would equate to two special needs moms hugging in the hallway of a hospital after just meeting for the first time? The two of us have stayed connected as our boys have gone through their difficult days, some much harder than others. At one point, mom had asked if I ever looked into Palliative Hospice Care. I had never heard of it. The only point of reference I had with the word "hospice" was end-of-life care. She gave me some more information and encouraged me to reach out to Capital Caring. After talking with my husband, we decided to at least schedule a phone call to get information about the program. Jackson qualified and it seemed to be perfect timing as he had just come home from a long hospital stay and his body was taking longer to bounce back. Having a nurse come to our house weekly to check on Jackson gives us great peace of mind. The care and attention provided to our entire family, has been amazing. When we first enrolled Jackson in this program I thought to myself, why has no one ever mentioned this amazing benefit to us? We've been dealing with this devastating seizure disorder for 13 years! My mission now is to help other families understand what benefits are out there and be available to them.

So back to my original question: When is social media more than just endless scrolling and a waste of time? When you make amazing connections with families all over the world, connected by such a thin thread, all because of a devastating, life-changing diagnosis. Social media has bridged the gap that physical distance creates. Good can come from bad and there is joy in the journey. With social media, parents do not have to walk the journey alone.

Seeking Peace Amidst Chaos

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As a pediatric chaplain, sometimes I am present when a child dies.

While each one is a unique experience, one thing is always true: It is always sad.

The death of a child is always sad. Whether they lived for many years or a few moments, whether it was expected or unexpected, whether it was the end of a chronic illness or an unexpected accident, the death of a child is always sad.

Often, the death of a child is terrible. Sometimes chaotic. So often it is unexpected and the family is blindsided and unprepared. In many instances, a few days prior the child was at home playing with the dog and eating a popsicle, and then something unimaginable happened, and today the family is trying to comprehend incomprehensible news.

For most, the death of a child is unimaginable. The situations where there is little or no opportunity to prepare are devastating. Maybe they are involved in an accident and a child goes from laughing to the end of their life in a matter of hours. Sometimes it is an aggressive disease that showed symptoms too late and the child and their family are dragged through awfulness to an abrupt end in a matter of days or weeks.

The deaths of children that are unanticipated, where a family is given no time to understand, comprehend, or prepare are awful. The teams providing care do their best to make it as compassionate and respectful as possible, but often they are adapting and adjusting to a set of circumstances thrust upon them and over which they cannot gain control.

Sometimes it is an event no one expected that requires an emergency response and there is no opportunity for preparation—for the patient, their family, or for the team. These situations require everyone involved to depend on their prior experiences, their established skill, and their instinctual reactions to make the situation as respectful as possible for all involved.

However, not all children die in the midst of chaos. There is something that most of the world doesn't know that those of us inside of a hospital might have witnessed: sometimes the death of a child can also be peaceful.

A dear colleague, and manager of our pediatric palliative care program, reflected that once she acknowledged the reality that she lives in a world where children die, she realized that maybe she could be with those children and their families so that they were not alone in their time of terribleness. In my experience with our palliative care program, that is what we do—in situations where people are facing some of the worst moments of their lives, we make sure they are not alone and do what we can to make it as peaceful as possible.

Even though many of these situations take a family and care team by surprise, there are also many times when there is an opportunity to prepare. Often, there is an opportunity to foresee that a child's life will end as the result of a disease. When that opening exists, a compassionate and caring team can do the work of preparing the context and the family as much as possible. These situations can be beautiful to witness.

Sometimes when a child dies, it can be peaceful. Sometimes it can be an experience that illustrates and exemplifies love in ways that can't be witnessed in most circumstances. Sometimes a disease progresses in a way that allows for a bit of preparation. Sometimes a family has an opportunity to understand that the unexpected injury and deterioration will never be reversed. Sometimes a family can see what is happening and has the available energy and personal wherewithal to be present to their child in loving, caring, beautiful ways in the last moments of that child's life.

Sometimes a care team has the time to build enough trust with the family to gain some insight into who they are and what values they hold dear. This relational connection can help the whole team work together to minimize the chaos surrounding this family and their child

The interventions are not always magnificent. Most often they are quiet and thoughtful. A team waits on the next step until a favorite relative can be present. A creative person figures out a way to fill the room with the smell of freshly baked bread. A parent is given the chance to bathe their child one last time. An adolescent gets to hear his beloved marching band play one more song. A complicated transport is accomplished so that a last breath takes place in a familiar setting breathing familiar air.

When these intimate and sacred moments are orchestrated, it is inspiring to watch a group of the most skilled and well-resourced professionals in the world collaborating across units and service lines in an effort to help a child and family as they face an unbelievable moment. The call goes out and people show up almost out of instinct. People who don't normally work together are able to join their efforts for this one common purpose.

In these situations, no one stops to ask if this child or family is worthy of this type of extraordinary care. Outside of pertinent physical details, no one stops to ask the kids race. No one stops to ask if her parents are straight. No one stops to ask how smart he is. Everyone knows they cannot eliminate the sadness of the situation, but there is a hope to make it as peaceful as possible.

It does not always go smoothly. The situations are often worrisome, there are frustrations, and some of the systems get crossed sometimes. But everyone shows up with a common purpose—to take care of whoever needs support. As always, the goal is to reduce injury and support life in all its forms when possible—no matter the patient's family structure or skin pigmentation.

I know many people who are reading this work in places and on teams that witness these events on a regular basis. I know some of you help children and their families prepare for these last moments. And you do it because you care for people. You know how sad the death of a child always is, you have seen how things can sometimes end in chaos, and you've also seen how things can end differently.

For those who do this delicate and gentle and beautiful and courageous work of caring for children, I hope you have the resources you need to do it in the ways that you know it should be done. In the face of these stories always being sad, I hope you have the personal bandwidth necessary to do it well while also keeping yourself healthy and whole. With you, I hope for a day where there is not a threat of a child dying. And until that day, I hope we are all able to continue to work to make those moments as peaceful as possible.

Even if Just for a Moment

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I often wonder if I'm going to offer any kind of peace to the patients and families I meet. Many of those families are in palliative care. A crisis is only a medical finding away.

Working in a children's hospital, as a family mentor, is something I've done for years. Wednesday afternoons are the golden hours of my week that I spend on the oncology floor at C. S. Mott Children's Hospital at the University of Michigan. My goal is to relieve suffering, even if just for a moment.

I guess it was a couple of years ago when I decided to try a new creative concept. This new way of having conversations has opened my eyes a bit and help light my way to seeing beneath the simple conversations of old.

"So, MaryAnn, I was wondering if you were to think of yourself as an inanimate object what would that be?"

I had known MaryAnn for about a year. We have had many conversations over her multiple admissions on seven east. Her daughter has bone cancer. After I asked her, she stared at me and I quickly tried to explain my intention before I lost her.

"Well, one time a mom told me she would think of herself as a pen and pad of paper because she wanted to rewrite her story, it was so sad."

I then added, "After we come up with an idea, MaryAnn, we can paint a picture of it." I then pointed over to my vintage art box and a primed, wooden panel sitting on the peninsula of the community kitchen counter. There are two bar stools there and a place where the magic often happens.

As she sat on the couch across from me in the family lounge, I followed up with her. I explained that the mom who wanted to rewrite her story, after starting to paint asked, "Is it OK if I change my mind, I now want it to be a pencil."

MaryAnn perked up and smiled, "Because it has an eraser?" she asked.

I nodded yes.

So, today, I thought I would share some of the photos of children, adolescents, and their families painting. Everyone has given me written permission to share.

1. Scott Newport and Olivia enjoying one of her good days.

2. She came in and said she wanted to paint a little girl. When she was done, I asked, "So what did you paint?" She replied, "That's me!"

3. His mother asked, "Is it ok if he paints? His brother has cancer." Of course, I said. I wanted to ask the boy why he painted one fish eating another, but left that for my imagination.

4. "Hey, can I paint today," he asked as we passed in the hall. He told me his head was full of knots as he was waiting for his bone marrow transplant. The top portion of the painting is his hope, the bottom is his past.

5. "This past year has seemed like a thunderstorm that won't stop."

6. Aaron and wife starting to paint in the NICU. When I walked into the church at their sons funeral the two paintings were displayed on a table full of recent memories.

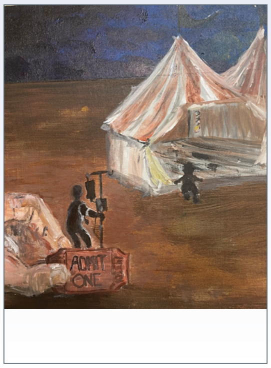
7. Arron's son had trisomy 18. "Scott, don't you want to know why I'm painting myself as an anchor." I thought I did. He then informed me that racing sailboats don't carry anchors because of their dead weight. He added, "Scott that's how I feel. I'm not doing enough to help my wife and family."

8. "She wanted to paint a memory from one of her favorite vacations. When I asked if her friends "got it." I said, "You know, all the medical stuff you're going through." She replied, "I don't have any friends now."

9. This mother said, "Scott, I want to paint myself as a locked door." While her son was dying we revisited the painting. I asked her if she saw it differently now. She replied, "Yes, I see paradise on the other side of the door now." I always loved that she put the word, "you" on the key. That she was just maybe the key that would open the door one day.

10. This woman started out wanting to paint herself as a bandage. Her soul was always bleeding and she wanted something to stop it. She then decided to paint a bandage over the crack on the liberty bell. In the end, no bandage and no crack. That day felt like there was some healing in the painting we did that afternoon. She told me the liberty bell was her symbol of freedom from cancer.

11. “Scott, when we came up to the oncology floor, I felt like I crash landed on an alien planet.”



12. This mother originally was going to paint herself as a compass to find new direction. After a week passed, she came up to me and said, “I was able to go home for a couple of hours last week. We live in a small town.” After we talked for a minute, she told me everyone in the local grocery store was staring at her. She said, “I felt like I was in a three ring circus, I couldn’t get over the whispers about there’s the mom with the sick kid.” I love the picture of her hand in the painting with the ticket that reads, “admit one.”

13. "I want to paint myself as a bird with broken wings falling from the sky."

14. Parents with a child with medical complexity. Mom painted a chocolate chip cookie because she was hungry, but then said, “I’m so sad I’m ready to crumble.” Dad was very mad at the doctors for asking the same questions over and over again, so he painted a wrecking ball breaking down a wall.

15. Even though he was worried about his upcoming bone marrow transplant, and wondered if it would work out, he wanted to paint a favorite memory of him in the marching band.

The Crucial Role of the Medical Interpreter: Focus on Pediatric Palliative Care Encounters

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The United States is a major immigrant-destination country, among others. We are serving a large share of immigrants from culturally and linguistically diverse countries. One in seven individuals in the U.S. was born outside the country; many identify as immigrants. Consequently, many families enter the hospital needing care for their children and are enduring the resettlement phase.

The laws supporting language access are ever evolving. It is strongly recommended to read on the requirements for language access for individuals requiring an interpreter. healthlaw.org/wp-content/uploads/2018/09/Federal-Language-Access-Laws.pdf

> *"If you talk to a man in a language he understands, that goes to his head. If you talk to him in his language, that goes to his heart," by Nelson Mandala.*

Interpreting in pediatrics is unique in comparison to other settings, because interpreters are dealing with young patients and caregivers. It is essential that the interpreter connects with the family and children while still abiding by the Code of Ethics. When interpreting for children, it is essential to preserve the tone of speech to successfully adhere to the provider's communicative technique. When professional interpreters are not used, the patient and/or family may have unsatisfactory understanding of diagnosis, prognosis, and goals of care. It is imperative to create a rapport with the interpreter assigned to the encounter because of the absence of standardized training in palliative care.

Something to keep in mind...

Low-income nations have limited resources, meaning that palliative care services are not feasible. That being so, the term "palliative care" is foreign to a portion of the Hispanic community, and therefore requires an explanation.

A lack of understanding of the limited English proficient patients' perspectives and how culture impacts the way an illness is viewed can lead to misunderstandings and communication problems during family meetings. Assessing how palliative care needs differ by language and culture is another important gap in the literature.

Listen Better	Speak Better
Listen with patience	Speak simply
Listen for key words, main ideas	Speak with structure (first, second, last, etc.)
Listen to body language	Speak in small doses
Listen to language level	Speak slower with greater enunciation
Listen without prejudice	Speak with your body

The role of the interpreter is as a conduit, clarifier/cultural broker, and advocate.

The interpreter's default role is as the conduit, and this is when the dialogue is converted into the target language. A trained interpreter will preserve the tone, register, and style. When professional interpreters are **not utilized,** the patient and/or family may have unsatisfactory understanding of diagnosis, prognosis, and goals of care. Maintaining accuracy is the goal, which is why a pre-session and post-session are highly recommended. The pre-session gives the interpreter the opportunity to prepare emotionally and for language complexity. The post-session is an opportunity to get/give feedback from/to the interpreter. ***It is crucial to create a rapport with the interpreter assigned because of the absence of standardized training in palliative care.***

The interpreter's secondary role is that of the cultural broker/clarifier with the expectations of being cognizant, observant, and sensitive of the diverse similarities and differences among a world of distinct cultural groups. It is essential to have cultural brokers in healthcare to help ease the distrust that various communities have towards health care organizations. Interpreters work towards changing interpersonal relationships with the provider team to break down barriers, bias, and prejudice with the aspiration of reforming the health care setting. Also, interpreters serve as a catalyst for change with the ambition to promote inclusivity and a collaborative environment for providers and patients alike.

Advocacy for an interpreter is a delicate balance in which they are to maintain impartiality and must navigate advocacy carefully to ensure effective communication and patient safety.

> *"Disparities in end-of-life care and quality of death are prevalent among immigrants. Immigrants in the United States are more likely to die in hospital settings and less likely to die at their preferred location."*

Provoking questions...

- How can interpreters manage emotional stress during palliative care discussions?
- What strategies can healthcare teams use to support interpreters in their role?
- Are there any cultural considerations specific to palliative care interpreting?

Who Dat? We Dat!

Our mission is to increase communication satisfaction and to encourage providers-to-family bonds. It is a privilege to collaborate so closely with the Hispanic community here in our hometown, New Orleans. We recognize the disparities occurring every day around us, and we are ambitious to collaborate closely with our providers here with the promise to provide equal health care.

(Left-to-right: Lilian, Yaira, Vanessa, Maythel, Marcia, Nathalie) **Meet the Children's Hospital 1st in-house interpreter team composed of 6 Certified Medical Interpreters/Translators.**

Building our skills...

Like all professionals, we must keep ourselves up to par with the changes in our field, including medications. We continue reading publications related to pediatrics and healthcare in efforts to enrich our vocabulary.

Who is qualified

Bilingual individuals should not interpret unless they have taken the formal interpretation course. Medical terminology is a specialized vocabulary for all languages and is not widely known. Family members should not be utilized to relay information for reasons of stress, proficiency, and comprehension. In today's circumstances most of us rely on the help of AI. Be wary of the use of online translation websites. I have personally been in situations where after-visit summaries, autism diagnosis, cancer medications, etc. are not translated correctly resulting in uncertainty.

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Communicating Wishes in Serious Illness: Based on the National POLST (Physician Orders for Life-Sustaining Treatment) Form

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Palliative Care Champion
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To share their wishes, an individual with serious illness may opt to have a "POLST" a document for out-of-hospital orders. This is completely voluntary. To be valid, such documents must be signed by the patient/parent (for pediatrics) or legal guardian and by a physician. They are only completed if desired to do so by an individual who is facing a serious illness. Traditionally, healthcare respects an individual's right to make healthcare decisions. "This is challenging in pediatrics when the child, by virtue of age or developmental capacity, may not be able to make decisions independently. Parents are tasked with making decisions in the best interest of the child."1 Shared decision making in pediatrics is endorsed by several prominent organizations including, the American Academy of Pediatrics (AAP), American Medical Association (AMA), the Association of Pediatric Hematology/Oncology Nurses (APHON), and the Hospice and Palliative Nurses Association (HPNA). "The child's voice is important to decision-making, however, not every child will want to participate in these discussions."[1]

A completed "POLST form," specific for one's state location, gives EMS and other health care providers the instructions for the treatment desired, such as Do Not Resuscitate or to proceed with CPR if indicated. Intensity of treatment and antibiotics are also covered, as well as if a feeding tube is an option or not. It allows an individual to share treatment desires and your goals of care which should be honored outside of the hospital.

Based on each state, they may adopt their own required document based on the National POLST form. "POLST are state-specific and are specifically for the seriously ill or frail, if presented, they will be honored by EMT's."[2] In pediatrics, it is important to have a collaborative approach to clearly communicate the wishes of an individual. "For children with a POLST form, the AAP recommends a collaborative approach, whereby schools, parents, clinicians, emergency medical services (EMS), and legal counsel review goals of care and POLST forms on a semi-annual basis."[3] This collaborative approach reinforces those specific desires for life sustaining treatment, to honor the wishes with dignity and respect.[4]

The name "POLST" has evolved to stand for "portable medical order," to maintain the focus and current thinking.[5] In this article, "POLST" will be used to address this form, regardless of distinction by state.

Many acronyms have been used for "portable medical orders" based on a state's interpretation and implementation of the National POLST form. Some of those acronyms are included below and provide the wide array of acronyms used based on the National POLST form.

- **POLST:** Physician Orders for Life Sustaining Treatment
- **MOLST:** Medical Orders for Life Sustaining Treatment
- **MOST:** Medical Orders for Scope of Treatment

- **TPOPP:** Transportable Physician Orders for Patient Preferences
- **Louisiana LaPOST:** Louisiana Physician Orders for Scope of Treatment
- **Oklahoma OKPOLST:** Oklahoma Physician Orders for Life Sustaining Treatment
- **New York MOLST:** Medical Orders for Life Sustaining Treatment
- **Texas MOST:** Medical Orders for Scope of Treatment
- **Missouri TPOPP:** Transportable Physician Orders for Patient Preferences

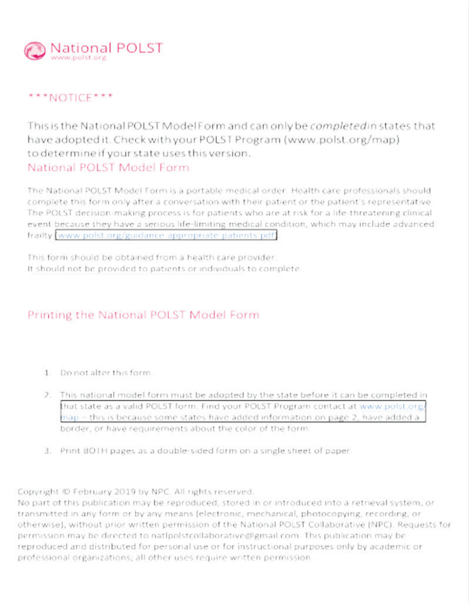
"A POLST directs your immediate care during a medical emergency. It tells EMTs, doctors, and other health care professionals what to do, and they are legally required to comply. Only seriously ill people with limited life expectancy should have a POLST."[6] Wishes for end-of-life care must be respectfully followed when showing the completed POLST form.

Some key points to consider with a POLST:

- May be used at any age, for individuals experiencing serious life limiting illness or who are medically frail.
- Portable orders for current treatment.
- Signed by patient/parent/legal guardian or decision maker.
- Must be signed by physician or advanced practice provider (APP), a nurse practitioner or a physician assistant, if allowed by state regulations.

It is particularly important to remember that a POLST is not a required document. It is a voluntary document which may or may not be completed. A code status in a hospital setting is only honored in the hospital setting. Once back in the community, to honor these wishes, a POLST can provide clear portable medical orders to support the care you wish to receive in the community or your home. It can be helpful to keep a copy posted where it can be easily seen, like on the refrigerator or bedside table. It is also important for your caregivers to have a copy to honor your wishes if needed. If you have completed a POLST from your specific state and you intend to travel to another state, be sure to have a form signed for that specific state. This will ensure your wishes are followed by emergency care providers when they are shown the completed document. These are sensitive wishes and once expressed, we should do all we can to support and honor these wishes.

POLST forms allow individuals to clearly consider and choose medical treatments in advance that they wish to receive, and identify those they do not desire to receive.[5] These documents are a guide to the care desired at end of life presented as a portable medical order, valid with signatures of physician and the individual or (parent or guardian with peds after shared decision making.)



National POLST
www.polst.org

NOTICE

This is the National POLST Model Form and can only be *completed* in states that have adopted it. Check with your POLST Program (www.polst.org/map) to determine if your state uses this version.

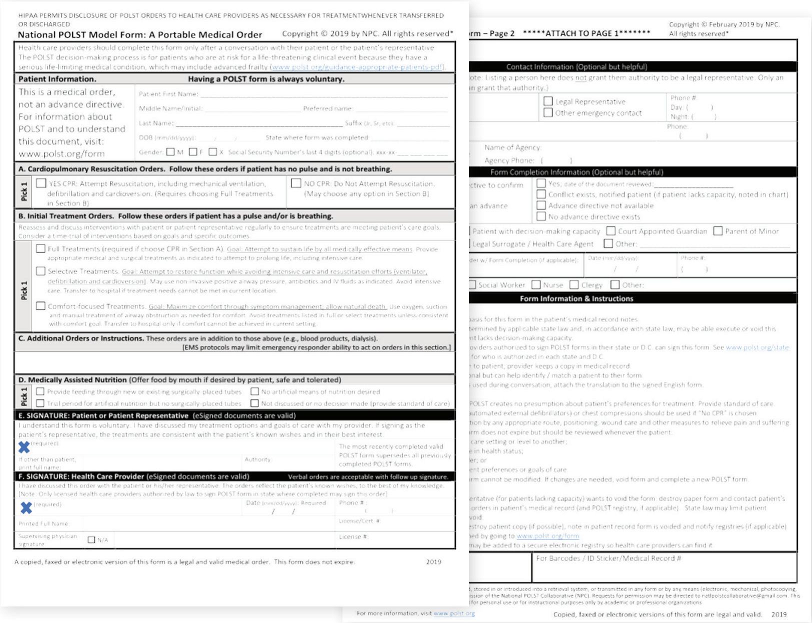
National POLST Model Form

The National POLST Model Form is a portable medical order. Health care professionals should complete this form only after a conversation with their patient or the patient's representative. The POLST decision-making process is for patients who are at risk for a life-threatening clinical event because they have a serious life-limiting medical condition, which may include advanced frailty (www.polst.org/guidance-appropriate-patients-pdf).

This form should be obtained from a health care provider.
It should not be provided to patients or individuals to complete.

Printing the National POLST Model Form

1. Do not alter this form.
2. This national model form must be adopted by the state before it can be completed in that state as a valid POLST form. Find your POLST Program contact at www.polst.org/map – this is because some states have added information on page 2, have added a border, or have requirements about the color of the form.
3. Print BOTH pages as a double-sided form on a single sheet of paper.



HIPAA PERMITS DISCLOSURE OF POLST ORDERS TO HEALTH CARE PROVIDERS AS NECESSARY FOR TREATMENTWHENEVER TRANSFERRED OR DISCHARGED

National POLST Model Form: A Portable Medical Order Copyright © 2019 by NPC. All rights reserved*

Health care providers should complete this form only after a conversation with their patient or the patient's representative. The POLST decision-making process is for patients who are at risk for a life-threatening clinical event because they have a serious life-limiting medical condition, which may include advanced frailty (www.polst.org/guidance-appropriate-patients-pdf).

Patient Information. **Having a POLST form is always voluntary.**

This is a medical order, not an advance directive. For information about POLST and to understand this document, visit: www.polst.org/form

Patient First Name:
Middle Name/Initial: Preferred name:
Last Name: Suffix (Jr, Sr, etc):
DOB (mm/dd/yyyy): / / State where form was completed:
Gender: ☐ M ☐ F ☐ X Social Security Number's last 4 digits (optional): xxx-xx-

A. Cardiopulmonary Resuscitation Orders. Follow these orders if patient has no pulse and is not breathing.

Pick 1
☐ YES CPR: Attempt Resuscitation, including mechanical ventilation, defibrillation and cardioversion. (Requires choosing Full Treatments in Section B)
☐ NO CPR: Do Not Attempt Resuscitation. (May choose any option in Section B)

B. Initial Treatment Orders. Follow these orders if patient has a pulse and/or is breathing.

Reassess and discuss interventions with patient or patient representative regularly to ensure treatments are meeting patient's care goals. Consider a time-trial of interventions based on goals and specific outcomes.

Pick 1
☐ Full Treatments (required if choose CPR in Section A). Goal: Attempt to sustain life by all medically effective means. Provide appropriate medical and surgical treatments as indicated to attempt to prolong life, including intensive care.
☐ Selective Treatments. Goal: Attempt to restore function while avoiding intensive care and resuscitation efforts (ventilator, defibrillation and cardioversion). May use non-invasive positive airway pressure, antibiotics and IV fluids as indicated. Avoid intensive care. Transfer to hospital if treatment needs cannot be met in current location.
☐ Comfort-focused Treatments. Goal: Maximize comfort through symptom management; allow natural death. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Avoid treatments listed in full or select treatments unless consistent with comfort goal. Transfer to hospital only if comfort cannot be achieved in current setting.

C. Additional Orders or Instructions. **These orders are in addition to those above (e.g., blood products, dialysis).**
[EMS protocols may limit emergency responder ability to act on orders in this section.]

D. Medically Assisted Nutrition (Offer food by mouth if desired by patient, safe and tolerated)

Pick 1
☐ Provide feeding through new or existing surgically-placed tubes
☐ No artificial means of nutrition desired
☐ Trial period for artificial nutrition but no surgically-placed tubes
☐ Not discussed or no decision made (provide standard of care)

E. SIGNATURE: Patient or Patient Representative (eSigned documents are valid)

I understand this form is voluntary. I have discussed my treatment options and goals of care with my provider. If signing as the patient's representative, the treatments are consistent with the patient's known wishes and in their best interest.

✖ (required)
If other than patient, print full name:
Authority:
The most recently completed valid POLST form supersedes all previously completed POLST forms.

F. SIGNATURE: Health Care Provider (eSigned documents are valid) **Verbal orders are acceptable with follow up signature.**

I have discussed this order with the patient or his/her representative. The orders reflect the patient's known wishes, to the best of my knowledge. [Note: Only licensed health care providers authorized by law to sign POLST form in state where completed may sign this order]

✖ (required)
Date (mm/dd/yyyy): Required / /
Phone # : ( )
Printed Full Name:
License/Cert. #:
Supervising physician signature: ☐ N/A
License #:

A copied, faxed or electronic version of this form is a legal and valid medical order. This form does not expire. 2019

rm – Page 2 *****ATTACH TO PAGE 1******* Copyright © February 2019 by NPC. All rights reserved*

Contact Information (Optional but helpful)

ote: Listing a person here does not grant them authority to be a legal representative. Only an
n grant that authority.)

☐ Legal Representative
☐ Other emergency contact
Phone #: Day: ( ) Night: ( )
Phone: ( )
Name of Agency:
Agency Phone: ( )

Form Completion Information (Optional but helpful)

ctive to confirm
an advance
☐ Yes; date of the document reviewed:
☐ Conflict exists, notified patient (if patient lacks capacity, noted in chart)
☐ Advance directive not available
☐ No advance directive exists

Patient with decision-making capacity ☐ Court Appointed Guardian ☐ Parent of Minor
Legal Surrogate / Health Care Agent ☐ Other:

der w/ Form Completion (if applicable):
Date (mm/dd/yyyy): / /
Phone #: ( )

Social Worker ☐ Nurse ☐ Clergy ☐ Other:

Form Information & Instructions

asis for this form in the patient's medical record notes.
termined by applicable state law and, in accordance with state law, may be able execute or void this
nt lacks decision-making capacity.
oviders authorized to sign POLST forms in their state or D.C. can sign this form. See www.polst.org/state
for who is authorized in each state and D.C.
to patient; provider keeps a copy in medical record.
nal but can help identify / match a patient to their form.
used during conversation, attach the translation to the signed English form.

POLST creates no presumption about patient's preferences for treatment. Provide standard of care.
utomated external defibrillators) or chest compressions should be used if "No CPR" is chosen.
tion by any appropriate route, positioning, wound care and other measures to relieve pain and suffering.
rm does not expire but should be reviewed whenever the patient:
care setting or level to another;
e in health status;
ler; or
ent preferences or goals of care.
rm cannot be modified. If changes are needed, void form and complete a new POLST form.

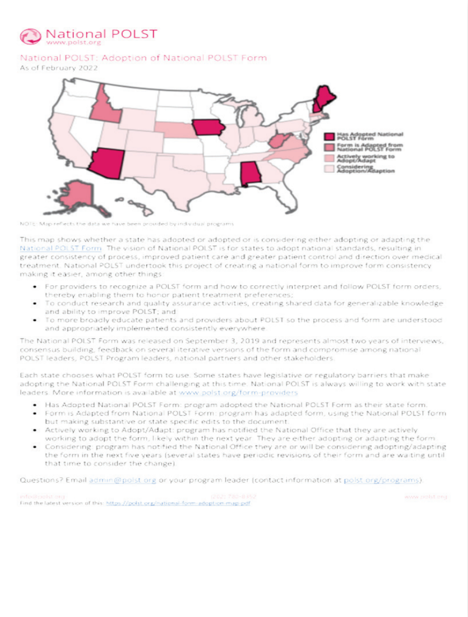
entative (for patients lacking capacity) wants to void the form: destroy paper form and contact patient's
orders in patient's medical record (and POLST registry, if applicable). State law may limit patient
void.
estroy patient copy (if possible), note in patient record form is voided and notify registries (if applicable).
ned by going to www.polst.org/form
may be added to a secure electronic registry so health care providers can find it.

For Barcodes / ID Sticker/Medical Record #

, stored in or introduced into a retrieval system, or transmitted in any form or by any means (electronic, mechanical, photocopying,
ission of the National POLST Collaborative (NPC). Requests for permission may be directed to natlpolstcollaborative@gmail.com. This
for personal use or for instructional purposes only by academic or professional organizations.

For more information, visit www.polst.org
Copied, faxed or electronic versions of this form are legal and valid. 2019

States may use this National form as a guide and adapt it to their own state standard.



National POLST
www.polst.org

National POLST: Adoption of National POLST Form
As of February 2022

NOTE: Map reflects the data we have been provided by individual programs

This map shows whether a state has adopted or adopted or is considering either adopting or adapting the National POLST Form. The vision of National POLST is for states to adopt national standards, resulting in greater consistency of process, improved patient care and greater patient control and direction over medical treatment. National POLST undertook this project of creating a national form to improve form consistency making it easier, among other things:

- For providers to recognize a POLST form and how to correctly interpret and follow POLST form orders, thereby enabling them to honor patient treatment preferences;
- To conduct research and quality assurance activities, creating shared data for generalizable knowledge and ability to improve POLST; and
- To more broadly educate patients and providers about POLST so the process and form are understood and appropriately implemented consistently everywhere.

The National POLST Form was released on September 3, 2019 and represents almost two years of interviews, consensus building, feedback on several iterative versions of the form and compromise among national POLST leaders, POLST Program leaders, national partners and other stakeholders.

Each state chooses what POLST form to use. Some states have legislative or regulatory barriers that make adopting the National POLST Form challenging at this time. National POLST is always willing to work with state leaders. More information is available at www.polst.org/form-providers

- Has Adopted National POLST Form: program adopted the National POLST Form as their state form.
- Form is Adapted from National POLST Form: program has adapted form, using the National POLST form but making substantive or state specific edits to the document.
- Actively working to Adopt/Adapt: program has notified the National Office that they are actively working to adopt the form, likely within the next year. They are either adopting or adapting the form.
- Considering: program has notified the National Office they are or will be considering adopting/adapting the form in the next five years (several states have periodic revisions of their form and are waiting until that time to consider the change).

Questions? Email admin@polst.org or your program leader (contact information at polst.org/programs).

info@polst.org (202) 780-8352 www.polst.org
Find the latest version of this: https://polst.org/national-form-adoption-map-pdf

"POLST exists at some level in 50 states and Washington DC: Existing is a spectrum from just having legislation passed, to implementing POLST with regional pilots, to having implemented POLST so it is standard of care within that state. While we have come a long way since the first POLST form was used in 1994, we still have a long way to go before POLST is standard of care and available across the country."6 As this development and adaptation of POLST continues, it is most important to hear the wishes of those with serious illness, we are humbled to serve and honor their final wishes with dignity and respect.

Below is a link to Improved Hawaii POLST Form 2023 step-by-step essentials with Dr. Daniel Fischberg.[7] It is an informative video to explain the POLST and process in development of the 2023 form for Hawaii. youtu.be/-NSupQGZU8o?si=ec5LYpZvtFRyZpv/

This link is focused on pediatrics and is very informative and insightful. Massachusetts Medical Orders for Life-Sustaining Treatment by A. Sanderson | OPENPediatrics.[8] youtu.be/-MXoCtP21xY?si=65fwKXhIJHKMuicq/

"Amy Vandenbrouke, JD, presented this as an opportunity for POLST leaders to hear about the process of creating the national form, discuss next steps and opportunities for future research and ask questions "(11/21/2019)[9] youtu.bebe/OPAPUOPZ7PQ?si=S3RIC4xG8V1OpACn/

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8. Massachusetts Medical Orders for Life-Sustaining Treatment by A. Sanderson | OPENPediatrics https://youtu.be/-MXoCtP21xY?si=65fwKXhIJHKMuicq/
9. National POLST Form: Materials, Q&A, and Next Steps, Amy Vandenbrouke, JD https://youtu.bebe/OPAPUOPZ7PQ?si=S3RIC4xG8V1OpACn/

Using Digital Resources to Support and Educate Caregivers and Clinicians

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Parents and other caregivers of children with serious illness constitute a population with a high need state. While individual experiences vary, needs can fall in nearly all aspects of daily life. Resources for this population are lacking. At the forefront, resources like home nursing and respite care are inadequate for many families. Community-based resources can be sparse or a mismatch for the unique circumstances in which they are living. There remain challenges in equitable access to pediatric healthcare. Unfortunately, these systemic problems are too often difficult to address for an individual family. Some needs, however, can be tended. Fortunately, some sources of support are within reach. When it comes to information, psychoeducation, and other supportive resources, we have greater ability to deliver *something* that will help.

As a pediatric psychologist, this is the space in which I live. Admittedly as a trainee, and early in my career, I had a narrow view of how these needs could be met. My graduate education focused heavily on skills like building rapport, assessment, and training in evidenced-based intervention. I supplemented my training with literature, mentors, and learning from each family that I met. I built a clinical repertoire that allowed me to be the conduit for intervention.

In the hospital, I met with caregivers who were journeying with their child, navigating acute and chronic conditions. Providing anticipatory guidance, teaching problem solving skills, validating and normalizing emotional experiences, delivering evidenced-based strategies to manage distress, sleep, and parenting, sharing strategies for communicating with their child's clinicians and social support networks, and imparting wisdom gained from other families were typical topics within encounters. Of course, my psychosocial colleagues in social work, psychiatry, child life, and other professions were doing similar work.

However, the reality is that all psychosocial providers are stretched thin. Despite many pediatric hospital settings touting the availability of robust psychosocial supports, the delivery of that support, and caregiver experience of it, varies widely among families. Provider time can be disproportionality spent with families exhibiting certain high need states. Focus is often on acute "problems," meaning other emotional needs get tabled. There just isn't enough time or resources to go around.

Fortunately, there are caregiver needs that can be met at low costs with big impact. This has become even clearer to me during my work at Courageous Parents Network (CPN). At CPN, we offer a range of digital resources for caregivers of children with serious illness (and pediatric clinicians). What I have come to understand is that not only can this be done well, it actually fills gaps in the care of caregivers. Importantly, it is a good compliment to, and can enhance the support delivered by, a clinician. CPN digital resources:

- **Are accessible**
  - Can be made freely available to caregivers and clinicians (and extended family members or others for whom the information is relevant)
  - Can be accessed at any time, from anywhere
- **Level the playing field**
  - ALL caregivers should have access to useful information. Access to what helps should not be dependent on resources or luck.

- **Prevent the perception of gatekeeping**
  - Caregivers wonder why they were not told information that clinicians know about. This can foster distrust in the relationship.
- **Bring evidenced-based information to caregivers**
  - What is the point of learning what is helpful to families in research but not sharing it with them? As a nonprofit, we work with clinicians to take and bring the latest expertise to those who need it
- **Allow for self-triage**
  - Clinicians often wonder when information should be introduced to caregivers. Clinical judgment is important when making this decision, but it is only an individual who can know for themselves what they need and when. Offer it digitally and let caregivers choose when they digest it.
- **Facilitate access to other parents**
  - Caregivers often want to hear from others with the same experience. Sometimes it's not feasible to make that connection. Sometimes there are downsides to engaging with other caregivers either in person or online. CPN brings the perspective of many parents to families, and without bias, and allows parents to choose who they listen to and learn from.
- **Are easy to share and deliver. Our digital resources can be integrated into Electronic Medical Records systems, making them easily shareable with families and colleagues.**
- **Help caregivers feel less alone and validated**
  - This is priceless. Reducing real or perceived isolation through the convening and delivery of family perspectives is a gift.

In my own practice, these digital resources have become an asset to my work. I send links to CPN guides or videos following therapy sessions with parent caregivers related to something we spoke about. I may suggest they listen to a few other parents before we meet again or recommend they take a guide to their child's appointment to help them think about questions they want to ask a clinician. Blog posts can support my advocacy efforts on behalf of caregivers, keeping their voice and perspective central.

Caregivers are going to search the internet. They will scroll their phones at night. We can help by sending them in the right direction.

Digital Platforms and Social Media in Pediatric Palliative and Hospice Care: The Positives and the Pitfalls

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The press is full of so many stories about social media from all vantage points, depending on who is posting, and what they are posting about. Therefore, it is not surprising that the same is true for the use of social media as it exists within the world of pediatric palliative and hospice care. A review of the literature and the popular press has numerous accounts of how parents of children with complex medical conditions find digital platforms a source of help and support. In contrast, some of the general public rails against parents when they post pictures or stories about the hardships of life with a "sick child" for a variety of different reasons. And pediatric palliative care and hospice providers are also caught up in this maelstrom of wanting to be supportive and offer hope to these parents, while knowing some of what is being shared is not trustworthy information and is often against accepted medical practice, medical ethics, and privacy laws. This article will explore some of the benefits and the "bad parts" of social media from different perspectives—parents, the public and providers—in an effort to help present some considerations of when, and how it can and should be used, and when it needs to be reined in or ignored altogether.

From the Viewpoint of a Parent of a Medically Complex Child

Hospice Provider Case: A wonderful 6½ y/o WM with normal (NL) past medical history presents to his pediatrician's office with new onset ataxia or inability to walk. He is subsequently evaluated by multiple specialists including neurologists, endocrinologists, and geneticists, and is diagnosed with X-Linked Adrenoleukodystrophy (X-ALD). This is a rare genetic metabolic storage disease of very-long-chain-fatty-acids (VLCFAs) that usually presents in males in early childhood and is deemed incurable. Although a few interventions are possible, most children are diagnosed later in the progression of the disease—making treatment options complicated. Nevertheless, some parents look to on-line support groups for suggestions.

The Role and Impact of Social Media and Other Digital Platforms: Often, when parents receive a devastating diagnosis for their child, they turn to the internet for information through search engines, health apps, medical websites, etc. They search for anything and everything they can find on the diagnosis, treatments, prevalence of the condition, what they can expect, cure rates, and any ounce of information that will help inform them of what they, and their child, is facing, but more importantly, how they get out in front of the diagnosis and get it cured, or at least controlled. They are not educated on what are reliable and unreliable sources of information, and especially early in a diagnosis, they really don't care. They need to get smart fast so they can manage the care of their child for the child's most favorable outcome, which is nothing short of complete eradication of the disease or medical condition in their minds.

In this internet searching, they find sites with other parents who are also struggling to learn about their child's condition and how to "fight" it with the best of what's available by way of treatments, surgeries, procedures, and more. These parents are "like them" through what they are experiencing, and bonds are often formed as they walk these day-to-day journeys with their children together in shared education and support. The literature indicates that parents and other caregivers of these medically complex children do in fact derive social and emotional support through these online peer relationships and support group interactions,1 which can be a good thing. From these online interactions, parents can become empowered with knowledge which leads to action on behalf of their child. However, what is not as well-documented is the impact of privacy and ethical issues that exist through parental use of these digital platforms like Facebook, Twitter, Instagram, email, etc., in addition to the negative consequences a medically complex child can suffer when parents follow healthcare treatment suggestions offered by other parents that are not evidence-based.

A literature review conducted by Geuebner et al., states that digital platforms are primarily used for two purposes—to retrieve information and for social support.[1] When seeking to learn more about their child's condition from digital platforms, parents are often looking for information to help inform them on the child's condition as well as where/how to seek out services and professionals who can help.[2-5] This is similar to what they're looking for when reaching out to other parents who have children with similar conditions or care pathways as theirs; however, in that process of consulting other parental posts via social media groups or online support groups, they also find an empathic support network which helps to reduce the isolation they feel on these medically complex journeys with their children.[4, 6-9] In a study by Ammari and Schoenebeck,[2] parents claimed that being able to communicate with these other parents offered them some hope, which in turn lessened their anxiety and depression after receiving their child's diagnosis. So for many parents whose child is diagnosed with some type of more serious medical condition or who is born with special needs, they seem to be empowered to better face these journeys with their children armed with information, hope, and support from digital platforms and other parental posts and support groups.

Hospice Provider Case Discussion and Thoughts: At the time of one of the patient's home visits, his mother mentioned a parent on-line group that she and her husband had recently joined. The group consisted of other adults who either currently had a child with X-ALD or had lost one in the past. Participants were able to post questions and discuss topics related to overall prognosis, treatment options, and familial distress. The mother seemed somewhat alarmed by some of the "medicinal" options that were given. For instance, one blogger taught the mother how to make a certain concoction using holistic ingredients including various types of oils that could then be given to the patient via his gastrostomy tube on a daily basis. No mention of possible side effects or risks were given, and the patient's mother admitted that the blogger designed the "medication" on her own accord. This information is not meant to dissuade anyone from accepting the possible benefit of holistic medicine options; rather, it is an attempt to demonstrate the misinformation that can often be found on certain websites. Vulnerable populations, such as parents who have children with chronic disorders, may be open to receiving suggestions due to their understandable need to help those they love. Being aware of possible consequences related to information that is often unfiltered is prudent.

From The Public's Viewpoint

Hospice Provider Case: A kind and unsuspecting 9 y/o WM presented for a follow-up visit shortly after being hospitalized at the local children's hospital. Children are allowed the opportunity to receive Concurrent Care in which they can still receive life-saving treatments while also receiving hospice care. This child needed assistance related to being on total parental nutrition (TPN) with the goal of weaning him off the treatment as suggested by the prescribing gastroenterologist. His mother seemed reluctant to start the wean and elected to terminate a clinical relationship when it was made clear to her that orders would not be written in order to prolong the unnecessary treatment.

The Role and Impact of Social Media and Other Digital Platforms: The general public does not appear to be as understanding, and therefore, as accepting, of parents of medically complex children posting news, updates, or images of their children on public social media forums. The act of doing this has even been coined as "sharenting," which according to some reports, is growing in popularity in today's modern world. One such negative response to posts like these is exemplified in these comments found on social media platforms including *"it irks me to no end to see people post photographs of their sick children on social media…I just think it is exploiting the child to get attention. Just makes me sad."*[10] *"People who post photos of their ill kids all over social media are some of the worst attention seekers. 'My child is ill - better take a photo and show all of my friends just how thoroughly miserable they are!' Urgh."*[11] and *"I agree. Maybe we are just uncaring and out of touch, but some of the things people post make me cringe. And I do think it's for attention in a lot of cases. These digital platforms encourage narcissistic behaviour."*[11]

Despite parents engaging in the act of "sharenting" on social media with good intentions, there are also privacy risks and ethical concerns that are present, most notably, the violation of the children's rights in having information about their illness or condition shared, whether the child is young and unable to speak for themselves but especially when the child is an adolescent or teen. This also includes the sharing of private health information which health systems work diligently at to protect via HIPAA, yet parents seem to so freely share on public social media forums without regard. This issue or protection of children's rights and privacy has become a hot topic in the literature, and it continues to be widely debated.

Hospice Provider Case Discussion and Thoughts: Although rare in presentation, the patient's mother was eventually formally diagnosed with Factitious Disorder Imposed On Another (FDIA) or Fabricated or Induced Illness by Carers (FII), once commonly known as Munchausen Syndrome By Proxy (MSbP). Almost three years passed before the child was placed in protective custody and nearly seven years until the mother was convicted in a federal courthouse for her actions that placed the patient in harm's way. Many parts to this case were quite disturbing to say the least, but what was probably the most gut-wrenching was the way that the mother was able to manipulate websites to garner money for the patient's "treatment." For instance, a GoFundMe account was arranged which provided a countless amount of money from unsuspecting family members and friends that eventually paid for various unnecessary surgical procedures. The patient was made to endure these interventions that included a partial resection of his bowel and total loss of his gall bladder. One might wonder if the patient's abusive situation could have been limited if his mother was not allowed to engage in "sharenting" his image and information with others.

Other Social Media and Digital Platform Issues

When Parents Have Identified or Seek out Treatments that are Not Evidence-Based

Pediatric palliative care and hospice providers know this kind of care is both a science and an art. However, they use their best professional knowledge and expertise to recommend care paths that are evidence-based; that is, that have some legitimate research behind them, even if it's early on. Where the quandary comes for pediatric palliative care (PPC) providers is when parents find treatments and "cures" available outside the U.S. which are not under FDA jurisdiction, and therefore, may not be efficacious or safe for the child. A family in Florida took their son with a rare brain cancer to Mexico where the child spent a month receiving a mix of FDA-approved drugs that are not available in the U.S. To cover the expenses of this, the family had to sell their home as none of the treatments were covered by their insurance due to the treatments being provided outside of the U.S. The child's latest MRI showed tumor reduction and the parents are planning to return to Mexico for more treatments shortly.[12]

When Parents Spend More Time Looking for Options or Help on Digital Platforms/Social Media vs. With Their Dying Child

Hospice Provider Case: An amazing 20 y/o WF with recurrent astrocytoma of her brain (malignant brain tumor) attempts to balance her own treatment goals and personal needs with that of the wishes of her mother. The patient views her remaining time as one she would like to spend at home with her family and friends, while her mother simultaneously browses the internet for other treatment possibilities.

The Role and Impact of Social Media and Other Digital Platforms: Families may become obsessed with trying to find any treatment, anywhere, experimental or otherwise, that offers some hope for relief of symptoms or side effects, or stretching even further, a cure. They spend so much time on the internet and social media platforms in this search, while their child's condition is deteriorating, or worse yet, their child is dying. While pediatric palliative care physicians are good at holding hope with parents, in instances like this, the physicians are cognizant the child has limited time left and they try to encourage parents to spend their time and energy with the child, not on the internet or digital platforms with mixed success.

Hospice Provider Case and Discussion: This case depicts a situation that plays out repeatedly in both the United States and other countries abroad. Balancing the autonomous wishes of a patient (interesting enough the patient was also a legal adult at this point in time), with the desires of a parent is often difficult. The mother's continual pursuit of other on-line "treatment options" intensified the angst that the patient eventually felt prior to her death. While attempting to demonstrate her love for the patient through the time spent on the internet, the real relationship once available to the mother became lost and the voice of the patient was often diminished.

When Parents Request Pediatric Palliative Care/Hospice Providers to Join and Participate in Their Social Networks

Hospice Provider Case: A wonderful 9 y/o WM with Juvenile Onset Huntington's Disease (JHD) initially received expected care from his hospice physician and other staff members without interference. However, the original supporting relationship developed avoidable strain when the patient's mother over-utilized the social media options that were available to her.

The Role and Impact of Social Media and Other Digital Platforms: PPC providers face dilemmas when asked by parents of their patients to be "friends" on their social media platforms. For the parents, they like that there is a professional participant (or several if they've extended the invitations to numerous providers in their child's circle of care) as it brings credibility and some sense of legitimacy to the platform in addition to potentially gaining access to professional advice should the provider(s) comment on the platform. However, for the providers, these invitations post conflict of interest issues and privacy concerns for participation, but conversely, can be seen as not being supportive of the parents if the invites to be "friends" aren't accepted.

All of these instances present professional dilemmas for pediatric palliative care/hospice providers for a variety of reasons including the harm unvalidated treatments could bring to the child, seeing parents lose precious time with their dying child, trying to hold hope with parents while grounding them in the reality of the situation, and the professional ethical and conflict of interest issues they raise if providers do participate in these parents' social media networks.

Hospice Provider Case and Discussion: Probably of no fault of her own, the patient's mother overstepped her boundaries while utilizing social media. Work emails and phone numbers that were given to her (similar to other family members) intended strictly to deliver patient care information when needed, eventually became a means to text private information. For instance, the receipt of images of the patient and his pets at parties or other functions became a weekly occurrence. Furthermore, the mother requested that she would be made a "friend" on the physician's private foreign on-line language learning program without first disclosing the desire to do so. What started out as a means to communicate became a hindrance to the provider's ability to give needed care to the patient.

Conclusions

In conclusion, it is clear that while parents' of medically complex children may benefit from their participation in social media, other online support groups, and the internet in general, this clearly needs to be balanced against: (1) the backdrop of public backlash they could face when posting, (2) the ethical concerns about the child's privacy and his/her ability to consent to the sharing of information and posting of pictures, (3) the misinformation and unvalidated or untested information they can be exposed to which could pose harm to their child, (4) the amount of time spent on these media vs. with their medically complex child or other children in the family, and (5) the issues and dilemmas that may be caused if there is communication with the child's providers outside of the professional's boundaries, among others.

While there are some positive benefits to parents of these children, there are also many pitfalls which need to be taken into consideration as pediatric palliative care and hospice providers navigate this slippery slope of supporting families utilizing digital platforms and social media as they support their child, as outlined below:

The Positives:

- Provides a means of and support parents and family members during stressful times
- Allows the possibility of garnering information that might otherwise go unnoted in a regular clinical setting
- Empowers parents to feel some form of inclusion in their child's treatment plan
- Diminishes isolationism, depression, and anxiety for some parents due to the support of social networks

The Pitfalls:

- The moral permissibility of these parents sharing personal and/or medical information or photos about their medically complex child including the issue of consent by the child (or the inability to provide consent due to a young age or medical condition)
- Feasibility of balancing time spent on social media versus with the patient (time loss)
- Thinning of boundaries needed in order to provide good patient care

Providers are urged to proceed with some caution and to use their best judgement when working with their patients and their parents alike who are digital platform/social media reliant, to ensure they are educated on what makes platforms reliable in seeking out medical information. Additionally, they should encourage parents to check medical information (e.g., treatments, medicines/homemade concoctions, etc.) they uncover through the internet or via parental social platforms with them prior to utilizing it in some way in the care of their child. Hopefully, some of the problematic uses of these platforms can be mitigated by communicating that the provider and parents are a team all working towards the same goal of ensuring the best care for the child on this journey. That the sharing of information being considered or acted on by parents, as garnered from outside sources like the internet or social media, with the child's provider is key to ensuring the care being given is in the child's best interest and aligned with information that is evidence-based or at least from a trustworthy source.

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When A Parent Loses a Child, there are No Words

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> *"I think it's odd that there's no specific word in the English language to describe a parent who's lost a child, yet there are words for people who have lost other loved ones, such as 'widow' or 'orphan'."*

The words above belong to Alice, the mother of a young son with spinal muscular atrophy (SMA). SMA is a genetic disease that affects the central and peripheral nervous systems, and voluntary muscle movement. It involves the loss of motor neurons in the spinal cord, as well as muscular atrophy (Muscular Dystrophy Association, 2023). There are several types of SMA and, unfortunately, the type Alice's son has is terminal, and he will likely pass away in his teens. Alice also explained that this is her second son with SMA; one of her older sons passed away from the disease several years ago. I'd like to say that I have no idea what Alice is going through, but regrettably I do; at least to some degree. My daughter, Caitlyn Elizabeth, passed away in 2010 of a neurodegenerative disease shortly before her eighth birthday. As the father of a deceased child, I was unsettled by the fact that I didn't make the same observation that Alice did; that there is no word in the English language for a parent who has lost a child. There is "bereaved parent" and similar expressions, but those aren't the same as a specific word. Aside from my personal experience with this topic, I also have professional experience, too. I am a cultural anthropologist who has spent a significant amount of time over the past few years working with seriously ill children and their families who utilize pediatric palliative care and hospice care. Many of these families have lost children or soon will. Professionally, I didn't pick up on the fact that there's no word for a parent who has lost a child either.

My lack of observation troubled me, and I thought about some of the infant and childhood mortality rates that peoples and communities face all over the world. In 2021, over 7 million individuals under the age of 24 died across the globe (United Nations Inter-Agency Group for Child Mortality Estimation, 2023). In 2021 alone, about 20,000 infants, 3,800 children aged 1 - 4, and 6,000 children aged 5-14 died in the United States (Centers for Disease Control and Prevention, 2023). These numbers from the U.S. don't include the deaths of teenagers above the age of 14 nor adult children. The reality is every year millions of parents lose a child or children.

Knowing this, and that there's no word for a parent who has lost a child in English, I asked several of my multi-lingual colleagues if they knew of words in other languages for a parent who has lost a child. Between them, my colleagues had familiarity with several languages, including Arabic, Cantonese, French, Hindi, Irish, Korean, Mandarin, Portuguese, Spanish, and Tamil. A few of them mentioned words or concepts that were similar to a word for a parent who had lost a child, but they were not exact. A colleague of mine who is fluent in Mandarin, said there is – 鳏寡孤独 (guānguǎ-gūdú) – which means someone who is alone or has no family, such as widows, widowers, orphans, and the childless. However, childless does not always mean that someone is a bereaved parent; they could have never had a child or their child could have moved away and is no longer a part of their life. Another colleague who has some knowledge of Arabic stated that there is أثكل (althaklaa) and that more specifically, thakla is a bereaved father and thaklti is a bereaved mother (Almaany.com, 2023). He was the only one of my colleagues who knew of a word for a bereaved parent.

An English-speaking colleague from here in the U.S., noted that she had a younger brother who passed when he was nine, and that her mother searched for a better way to describe herself other than "bereaved mother," but it was the only option she knew of. Her mother came across the word "vilomah" and thought about using it because it was the only word that came close to how she felt, but it would have been more traumatic for her to constantly explain the meaning of "vilomah" than to just say she was a bereaved mother.

I wasn't familiar with the word "vilomah," so I Googled it. It was first suggested for use by Karla Holloway in 2009. Holloway is a professor of English at Duke University and a bereaved parent herself. She explains, "I returned to the language [Sanskrit] that had already given us one word (widow)…And I found 'vilomah'…Vilomah means 'against a natural order.' As in, the grey-haired should not bury those with black hair. As in our children should not precede us in death."

"Vilomah" has also been suggested by Fan (2020) and Grant (2022). While it is used to some degree, as a basic Internet search will reveal, it has not been embraced and most Americans are not familiar with the word. According to a colleague who is familiar with Sanskrit, the way in which Holloway and others are, using "vilomah" is not entirely correct. It does mean against the natural order, but it doesn't mean the loss of a child; in this case, it is an interpretation and adaptation of the word. As an anthropologist, I understand that words and concepts, as well as many other things in the human experience, are in a dynamic state and constantly changing. However, as I thought about the word "vilomah" and this idea of it being against the natural order, I was conflicted. As previously noted, millions of children die world-wide every year. Granted many of these deaths do not need to occur as they are not related to biological processes or genetic diseases, but rather to social and political factors tied to systemic poverty, inadequate access to healthcare, abuse, neglect, and violence. Regardless, these deaths do happen. And has been said time and time again, parents should not outlive their children, but they do. Cultural, socially, and maybe even religiously and spiritually, it is against the natural order.

If the loss of a child is as common as the numbers suggest, then why is the English language, as well as other languages, lacking a word to describe a parent who have lost a child? Aside from the few mentioned above, and the Hebrew word, שכול (so''khol), which translates as "bereavement," but is used to describe a family member who loses someone prematurely or at a young age, often due to war or terror related incidents (Rosbrow, 2012), an internet search and literature review reveals very little. Jude Gibbs, a counselor and author on parental grief, as well as a bereaved mother, believes that words do not exist "because words fail us…Words do not describe us…the level of pain that accompanies losing a child cannot be measured with a word" (Halloway, 2009). I agree; words do fail us. As I have expressed previously (Daley, 2023), one phrase that resonates with me comes from the Diné, or Navajo, who refer to cancer as "the sore or wound that does not heal," or 'lhóód doo nádzihii (Csordas, 1989). For some bereaved parents, the loss of a child is a sore or wound that never heals, and just like cancer, it can eat away at you until nothing is left.

Furthermore, as noted by Vasquez (2022), the loss of a child fundamentally changes a parent's identity. She states, "For those who were parents to an only child who died, who did they become afterward? Could they still call themselves parents if their only child died? How would they tell others that they once were parents, but now they're not?" (Vasquez, 2022). You are a mother or father, and then you are not; so, what are you?

Being a bereaved parent and a parent to a living child or children can also be an issue in itself. When people ask about your children, you have to decide whether to only talk about the children who are living and leave the deceased child out of the conversation, or bring up the child who has passed and deal with the questions that will inevitably follow. It is a no-win situation. If you do not mention the child who passed, you often feel badly for not doing so, but if you do, then your deceased child can become the center of conversation eclipsing any discussion of your living children and dredging up memories and feelings you may not want to discuss.

According to therapists, finding the right word to describe not only your pain, but who you've become after your child's death is an important and necessary part of surviving this loss (Vasquez, 2022). I would argue, however, that we don't need a separate word or a right word for a parent who's lost a child because that word already exists—parent. I spent almost eight years being Caitlyn's father, and while things may have changed greatly, as her father, I still have responsibilities, obligations, and commitments to her and her mother, my wife, Chris, as well as to other family members and friends. Put it into a sports analogy, she may not be able to play in the game, but she is still on the roster.

The death of a child is complicated and not easy to navigate. Cultural practices, social norms, linguistic limitations, and biological realities all intersect and collide here. Human emotions and individual behaviors and responses also come into play and further complicate matters. As such, I can't speak for all bereaved parents, nor would I want to. However, at least for me, a shift or reframing of the idea of what it is to be a parent is what is needed, not necessarily a new word.

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Pediatric Palliative Care: Why We Should Talk About It

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In this article, we will review some recent work highlighting the critical importance of advocating for pediatric palliative and hospice care services. We will briefly compare palliative and hospice care for pediatrics and aim to demonstrate the growing need for enhanced communication to address the challenges in accessing these services. Throughout this article, the following definitions apply:

- **Prenatal:** before birth
- **Perinatal:** 22 weeks gestation to 7 days after birth
- **Neonatal:** birth to 1 month
- **Infancy:** 1 month to one year of age
- **Childhood:** age 1 to 12
- **Adolescence:** ages 13 to 17
- **Young adulthood:** age 18 years and over
- **The term** *"living with a serious illness" is applied to define complex, chronic, and critical conditions that meet qualifying definitions for palliative and hospice care support.*
- **Palliative care includes hospice care.**
- **Hospice Care addresses the end-of-life.** Eligibility is most commonly a prognosis of 6 months or less and active decline.

There is no clear number of children who would benefit from pediatric palliative care; estimates range from 1-2 million in the U.S. However, data are inconsistent, and no definitive source exists to identify these children. We do know that the population of children and families that would benefit from hospice and palliative care is growing with the improvements in medical technologies and with the increase in pediatric trauma (NHPCO, 2023).

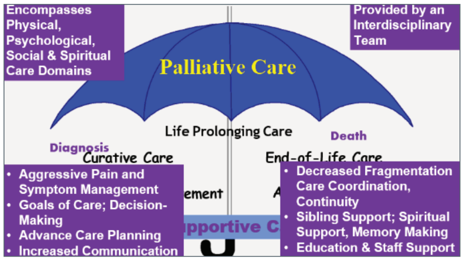


Figure 1: Palliative Care is the umbrella from the

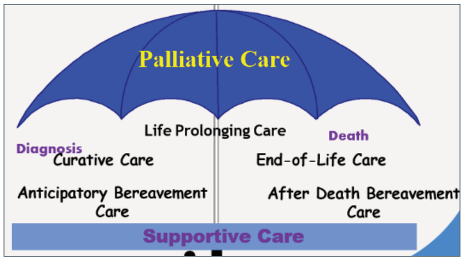


Figure 2: The tenets of palliative care time of diagnosis through bereavement

The differences between adult and pediatric care are significant and can be challenging. The size of a child's community is much greater, conditions can be much more complex, and often, providers have not cared for anyone with a similar pediatric condition. The number of children with life-limiting conditions is increasing, the number of children who could benefit from Pediatric Palliative Care/Hospice Care (PP/HC) is also increasing. This may mean PP/HC providers may only serve one to five children per year in certain areas, while others may have a census in the hundreds. Children with palliative and hospice needs range in age from prenatal to young adult.

Note: In most states, the Medicaid definition of children is prenatal to 21 years. (CMS.gov)

Differences between pediatric and adult care can be from several different perspectives, including:

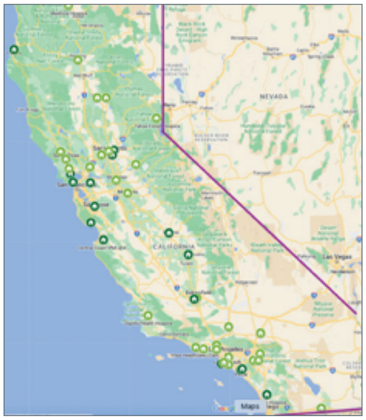
- Types of diagnoses
- Trajectories of illness
- Funding mechanisms
- Educational needs
- Ethical concerns
- Communication strategies
- Staffing management
- Care Coordination
- Prognostic uncertainty
- Lack of autonomy for hospice agency
- Circle of Care includes definition of family, community, degree of impact
- The complexity of collaboration with the child's broader medical team

Why we should be talking about pediatric palliative care. Recent research demonstrates the critical need for increased access to pediatric palliative care and Hospice services those who are eligible. We outline three examples below:

Case 1.

California is the most populated state in the US and is arguably home to the largest population of children with medical complexity. However, as demonstrated on this map, there are significant 'deserts' where there are no palliative or hospice providers and limited home care providers for our pediatric patients and their families.

This picture shows hospices that accept pediatric patients in the state of California, as shared by the Children's Hospice and Palliative Care Coalition of California. This resource can be accessed at www.chpcc.org/resources



Case 2.

Dr. Lisa Lindley and her team at the College of Nursing, University of Tennessee, Knoxville, has spent over a decade researching end-of-life care for pediatrics. Their website Pediatric End-of-Life Care Research has a wealth of information and tools to assist in advocacy efforts. Recently, Dr. Lindley and her team reported on adult hospices in California who care for children between the years of 2018 – 2021. As stated in their report,

> *"... hospice is increasingly providing essential pediatric services to children and their families. Children are increasingly utilizing hospice services – and concurrent care for those are eligible. 30% more children are seeking hospice care over the past decade, but the percentage of hospices in with pediatric experience & special pediatric programs has steadily declined over the past decade, especially in California."*

Because of the shortage of pediatric hospices, many adult hospice programs would care for pediatric patients. Dr. Lindley and her team looked at market characteristics, the mission of the hospice, the type of operation and the financial characteristics of these adult hospices. They found that the majority of hospices served urban areas with most of them in Los Angeles as noted by the cluster in the map shown above. Overall, however, the number of adult hospices that will care for a pediatric patient has decreased by 32% over the period of their review. During this same time frame, California saw an increase of for-profit hospices by 33% and a corresponding decrease in not-for-profit hospices by 30%.

Case 3.

The National Hospice and Palliative Care Organization (NHPCO) published the *Pediatric Facts and Figures, 2023* edition in 2023. This document is open access, as are most of the NHPCO pediatric resources. This report highlights the findings of national surveys of palliative and hospice services and is utilized by researchers, advocates, educators, and others.

The content includes:

- who receives pediatric palliative and hospice care,
- where the services are provided,
- how care is reimbursed,
- who provides care,
- what services are provided and
- what are the barriers and facilitators to care.

A sample of the key findings include the facilitators (#1 trained staff in pediatrics) and barriers/challenges to the provision of pediatric palliative care. Not surprisingly, the most common barrier was lack of pediatric trained personnel. However, one of the most concerning findings was the number of free-standing children's hospitals in the United States who reported access to community-based hospice services for their patients. Between 2016-2019, the percentages of hospitals that reported access averaged 40%. However, in 2020 that number dropped to 26%. This is consistent with the finding in the state of California.

If we do not continue to discuss the need for services for our most vulnerable children and their families, this downward trend will continue. The challenges are significant and include reimbursement, care coordination, workforce shortages, training, and education to improve services and access. However, if we use our voices and partner with our state coalitions and national organizations, we can make a difference. The goal? Access for all children and families who want and would benefit from pediatric palliative care to receive quality, holistic palliative care at any point in the trajectory of their illness.

References

National Hospice and Palliative Care Organization, (2023). Pediatric Facts & Figures. 2023 edition. https://www.nhpco.org/wp-content/uploads/NHPCO_Pediatric_Facts_Figures_2023.pdf

Davis, H., Weaver, M. S., Torkildson, C., & Lindley, L. C. (2023). Understanding adult hospices in California who care for children, 2018-2021. American Journal of Hospice and Palliative Care, 41(8): 911-919. https://doi.org/10.1177/10499091231204941

U. S. Department of Health and Human Services, (2023). NIH style guide: Age. https://www.nih.gov/nih-style-guide/age#:~:text=Adolescents%20(13%20years%20through%2017,adults%20(65%20and%20older)*

Weaver, M.S., Chana, T., Fisher, D. Fost, H., Hawley, B., James, K., Lindley, LC., Samson, K., Smith, S.M., Ware, A., & Torkildson, C. (2023). State of the service: Pediatric palliative and hospice community-based service coverage in the United States. Journal of Palliative Medicine, 26(11), 1521-1528; http://doi.org/10.1089/jpm.2023.0204

Resources

- Children's Hospice and Palliative Care Coalition of California: www.chpcc.org
- Pediatric Palliative Care Coalition of Pennsylvania: https://www.ppcc-pa.org/
- Pediatric End-of-Life Care Research: https://pedeolcare.utk.edu
- National Hospice and Palliative Care Organization: www.nhpco.org/pediatrics
- Hospice Action Network Policymaking 101: https://hospiceactionnetwork.org/wp-content/uploads/HAN-Policy-Making-101_Final.pdf
- List of Statewide Pediatric Palliative Care Coalitions: https://www.ppcc-pa.org/advocacy-2/statewide-ppcc-coalitions

Items of Interest!

Please help us keep the items of interest up-to-date. Share your news, upcoming conferences, or webinars. Are there particular podcasts that may be of interest to our readers? Send any items of interest to Christy at Christy.Torkildson@gcu.edu. Thank you.

Upcoming Conferences/Webinars:

- The 2024 NHPCO Annual Leadership Conference will be on September 14-18, 2024.
- The HPNA Team Conference for Hospice and Palliative Care will be on September 28, 2024
- The NAHC Home Care and Hospice Conference and Expo will be on October 20-22, 2024
- ELNEC **has several upcoming courses; if you are faculty, you can get free access to the curriculum for your program/courses you teach.**
- The AAHPM & HPNA Annual Assembly 2025 will be in Denver on February 5-8, 2025-.
- **Have a conference to submit/share – send us the information to** Christy.Torkildson@gcu.edu.
- Pediatric Palliative Care Webinar Series **for 2024 has been announced. Calendar and more information are available.**

Subjects and Contributors for Future Issues of this E-Journal

Our future issues will be centered on the following main themes. If you have any thoughts about these or any other topics, contributors, or future issues, **please contact Christy at** Christy.Torkildson@gcu.edu **or Melissa Hunt at** melissa.hunt@optum.com.

Issue Topics: 2024

- **Issue #77:** Home Care; Contributions due September, 2024
- **Issue Topics:** 2025: We Welcome Your Suggestions for 2025 editions of the Pediatric e-Journal. **Please email us at** pediatrics@nhpco.org **or Christy at** Christy.Torkildson@gcu.edu

NHPCO Pediatric Website Pages have been updated for easier searching!

NHPCO Palliative Care Online Resources:

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

- Community–Based Palliative Care
- Legal and Regulatory Resources
- Pediatric Concurrent Care
- Resources for professionals and families
- 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

Note: Many of the pediatric resources are open access as a community service by NHPCO and membership is not required. However, we would love to have you join our community of vested professionals focused on quality palliative and hospice care throughout the lifespan!

Did you know that the **State Coalitions from Pennsylvania, Illinois and California, with support from the Shiley Haynes Institute for Palliative Care,** host monthly, affordable webinars with continuing education units available? You can register for one or the entire series, with discounts for multiple registrations. For more information, review the PPC website.

Another great new group is the Child Life in Hospice and Palliative Care Network, which provides child life specialists working in hospice or palliative care access to resources, education, research, and networking opportunities to establish and provide best practice care for patients and families experiencing a serious illness. They are requesting that interested members fill out a brief survey, sign up today at CLHPN

Pediatric Hospice and Palliative Care Resources:

- **Courageous Parent's Network** has a wealth of resources for parents, caregivers, and providers. The list is too long to add here so please check out CPN's website.

- **The Pediatric Palliative Care Coalition of Pennsylvania, the Greater Illinois Pediatric Palliative Care Coalition, and the Funeral Service Foundation** have created a community resource to guide families through the funeral/memorialization planning process: ***When a Child Dies: Planning Acts of Love & Legacy.*** This resource is available in both English and Spanish and is **FREE,** thanks to generous funding from the Funeral Service Foundation. You pay only a nominal shipping fee. More information can be found at When A Child Dies.

- **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

- **NHPCO's Palliative Care Resource Serie**s includes pediatric palliative resources like:
  - 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
  - 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
  - In an effort to standardize the medication coverage process for children receiving concurrent care, the NHPCO Pediatric Advisory Council developed a new resource for providers titled
  - Determination of Hospice Medication Coverage in CHILDREN.

- **The Pediatric Palliative Care Coalition of Pennsylvania** (PPCC) has made a new resource available – a Sibling

Grief and Bereavement Toolkit. This Toolkit has been developed to address the needs and concerns of children and teens who have experienced the death of their sibling with medical complexities. Please see the associated article in this edition! Below is a link to the toolkit and one of the activities – "Make a Feelings Chart".

- **Questions about Concurrent Care?** Dr. Lisa Lindley and her team have created a wonderful website full of resources and information. You can access all the information for **Pediatric End-of-Life Care Research** at https://pedeolcare.utk.edu/
- 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.
- **A Toolkit of Autism, Grief, and Loss Resources by Hospice Foundation of America:** The toolkit will include a variety of materials and resources, such as:
  - suggestions for responding to the grief experiences of autistic adults;
  - ways to provide for choice and inclusion in rituals;
  - tips for communicating the news of death;
  - social stories on grief for adults;
  - videos about grief, including interview clips with autistic adults and their families;
  - two complimentary continuing education (CE) programs for professionals; and much more!
- **Palliative Care Resources for Nurses, Patient Care Support Staff, and Families of Patients by Life and Death Matters,** https://lifeanddeathmatters.ca/ offers texts, workbooks and resources for providers and family members. Although primarily focused on adults they reference across the lifespan with sound principles that are useful no matter the age of your patients.

The text, workbook and companion resources support nurses and nursing students (in Canada and USA) to develop the knowledge, skills, and attitudes for integrating a palliative approach and providing excellent end-of-life care.

Do you have a resource that would be helpful for others to know about? Please send the information to Christy at Christy.Torkildson@gcu.edu and we will add it to the Items of Interest.

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