

Care Throughout the Dying Process

ISSUE #60 | AUGUST 2020



Pediatric E-Journal

PEDIATRIC ADVISORY COUNCIL

Released in collaboration with the National Hospice and Palliative Care Organization



NHPCO

National Hospice and Palliative
Care Organization

Pediatric e-Journal

Pediatric Palliative and Hospice Care

Issue #60; August 2020

Issue Topic: Care Throughout the Dying Process

Welcome to the 60th issue of our Pediatric e-Journal.

This issue of the Pediatric e-Journal is focused on various aspects of care throughout the dying process as related to pediatric palliative and end-of-life care. This issue was planned over a year ago and we could not have imagined the world in which we find ourselves now with the coronavirus pandemic. Although older adults have suffered the brunt of the infection, the challenges that this pandemic has created affect all of us. Not only have we had to create different ways of being, we have had to create different ways to provide care and services to all populations. For many, there have been significant disruptions.

We do not make light of the current situation and plan to revisit this topic, and the lessons learned from it, later in a future issue in a way that is commensurate with its significance. In the meantime, while we offer this issue's collection of articles on various aspects of care throughout the dying process in connection with pediatric palliative and end-of-life care, we also invite you to share some of the challenges and opportunities the pandemic has brought to your personal and/or professional life. If you would like to contribute to a future issue on the coronavirus pandemic, please contact either Christy Torkildson at Christina.Torkildson@bannerhealth.com or Ann Fitzsimons at ann@here4U.net.

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 Ann Fitzsimons. Chuck Corr is our Senior Editor. Archived issues of this publication are available at www.nhpc.org/pediatrics.

Comments about the activities of NHPCO's Pediatric Advisory Council, its e-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are currently discussing topics such as self-care for the next issue in 2020 and lessons learned from COVID-19, telehealth & hospice/palliative care, and racial inequities/social injustice for issues in 2021. If you have any thoughts about these or any other topics, contributors, or future issues, please contact Christy at Christina.Torkildson@bannerhealth.com or Ann at ann@here4U.net.

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Issue #59: Care Throughout the Dying Process

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

How to Welcome Death

p. 6

Abby R. Rosenberg, MD, MS, MA

This insightful poem explores different ways of welcoming the arrival of death.

Parents’ Insights on a Child’s End of Life

p. 8

Blyth Lord and Members of the Courageous Parents Network

In this article, members of the Courageous Parents Network, each of whom has experienced the death of a child, comment on some of the most common questions that parents have about such encounters and offer insights about how to cope.

Changing the Narrative of Pediatric Death and Dying: The Story of a Bereaved Parent Serving as an End-of-Life Doula and Home Funeral Guide

p. 13

Toula Saratsis, Angelica's Mother

Here a mother describes the journey she and her daughter traveled from a diagnosis of a serious condition at 3 months of age to the child’s death at nearly 7 years of age. These experiences eventually led Angelica’s mother to become an end-of-life doula and a home funeral guide.

Kids and Death and Dying: A Reflection

p. 17

Ann Fitzsimons, BS, MBA

This article reflects on how the author’s children reacted to three separate encounters with death: a viewing of one grandmother, the dying of another grandmother, and that death of the author’s sister (the children’s aunt). The author offers guidance in responding to the needs and often unexpected questions from the children.

Artificial Nutrition at the End of a Child’s Life

p. 21

Suzanne S. Toce, MD, FAAP

Throughout many issues of our Pediatric e-Journal, we have come to expect from Dr. Toce clear, well-written, authoritative, and helpful guidance on a variety of difficult subjects. This article on managing artificial nutrition and hydration (ANH) and promoting comfort when a child is nearing end of life is no exception. The article concludes in this way: “Decreasing, withdrawing, or withholding ANH is a medically, ethically, and legally available option and should be considered as part of palliative care at end of life if indicated. Parents and the medical team can be assured that this is an available option to further comfort at end of life. However, because of emotional associations with ‘feeding,’ the shared decision making can be stressful.”

Assessment in Memory and Meaning Making: Intentionality as a Child Dies

p. 25

Hania Thomas-Adams, MS, CCLS, and Marta Friedman, LCSW, ACHP-SW. JD

This article offers a conversation between two experienced providers of care at the end of a child’s life. They discuss the very serious and thoughtful reflections that enter into their thinking

when they assess what, if any, are the best ways to promote memory and meaning making in such situations.

Memories & Milestones: The Importance of Intangible Legacy Building p.30

Heather Eppelheimer, BA, CCLS, CPLC

Here is a different approach to memory making at the end of a child's life. In this case, the focus is not on producing tangible objects, but on creating significant activities that can involve both the child and the family in meeting their needs and desires, such as staging a high school "graduation" or creating a "prom." The article concludes: "In the end, a question we should always ask the families and patients we serve is, 'What are your hopes, dreams, or goals for you (patient) or your child?' We should strive to listen and honor those requests in creative new ways."

Advance Care Planning with a Teenager: Empowering their Voice and Choice at the End of Life p. 34

Christina Benki, PhD; Maggie Root, RN, CPNP-AC, CHPPN; & Jennifer Adams, LCSW, ACHP-SW

This paper is a reflection on the therapeutic relationships developed between a pediatric palliative care team, hospice, and a mother and her daughter, and explores how early conversations about the end of life (EOL) can lead to profoundly meaningful changes in quality of life. Individual perspectives from three different providers are shared (Social Work, Psychology, and Nurse Practitioner) along with references to literature and reflections on the legacy of this special patient on our own learning in palliative care.

Addressing Disparities in Pediatric Palliative Care in the Context of Death and Dying p. 51

Neela Penumarthy, MD, MAS

In this article, the author notes that current issues within our culture and the experiences of many providers of care "require that medical systems look within to interrogate and diagnose their complicity in perpetuating inequities." She acknowledges that "the ability to effectively study pediatric palliative care disparities is currently limited, due to a lack of meaningful data." However, after citing some pertinent studies, she notes that pediatric palliative care providers "care for society's most vulnerable and thus are uniquely positioned to collect patient information critical to improving our understanding of disparities. We are in our infancy of understanding the complex ways that disparities in pediatric palliative care can reveal themselves, and further exploration is sorely needed. But recognition of the problem—the existence of inequities and the lack of adequate data collection to inform palliative pediatric disparities research—is a prerequisite to managing it...The difficult work of recognizing and studying these disparities is an important step toward providing more compassionate and equitable care for the patients and families we serve."

Silenced Suffering in Second Trimester Pregnancy Termination p. 55

Jane Zimmerman, LCSW

Here the author notes that "the evolution of prenatal diagnosis and obstetrical practice over the last 50 years has improved the safety of women and infants in astounding ways, making possible vastly improved outcomes for both mothers and babies. But it has also presented

parents with the need to make decisions of tremendous complexity and moral quandary about their children’s wellbeing, through the option of pregnancy termination in the second trimester for genetic or medical disease.” Accordingly, “this article explores the unique challenges experienced by these parents, the significance of clear and empathic communication by medical personnel, and the critical foundation this communication creates for parental recovery from the loss of their child.” In the end, the author shows that thoughtful and empathetic care can lead to the following results: “The memory of this lost child, released from guilt and blame, can then remain alive with parents down the years, as all lost children do, grieved and cherished for what was and might have been.”

How to Hospitalize a Child Receiving Concurrent Hospice Care

p. 61

Lisa C. Lindley, PhD, RN, FPCN, FAAN, and Alexis Morvant, MD, MA, FAAP

The authors of this article acknowledge that “the landmark pediatric end-of-life legislation known as Concurrent Care for Children (CCC) authorizes state Medicaid Offices to provide children, who are less than 21 years old and living with a six-month prognosis, with hospice care and subspecialty care. This benefit ensures that parents are never forced to decide to stop life-prolonging therapies in order to receive quality care at home from an interdisciplinary hospice team focused on comfort.” However, some unexpected complications have arisen in coordinating hospice and subspecialty care as illustrated in a case example. To ameliorate such complications, the authors recommend “7 steps to hospitalize concurrent care children, based on clinical experience and emerging best practices.”

Readers’ Corner

p. 65

Suzanne S. Toce, MD, FAAP

This Readers’ Corner focuses on an article that offers “a wonderful commentary with a topic that is pertinent to this issue of the e-Journal.” The article in question is by Hannah L. Kushnick on “Trusting Them with the Truth: Disclosure and the Good Death for Children with Terminal Illness.” To help readers, Dr. Toce summarizes key points in this article, clarifies its appropriate audience, explains what is special about it, and shows where and how its information can be applied.

HOW TO WELCOME DEATH

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"You are not welcome here," she told HIM
The first time He came.
And so she fought Him
With scalpels and machines.

"We are still not ready," she lamented
The next time He came.
And so she resisted Him
With antibiotics and plastic tubes.

"We need more time," she whispered
When He came again.
And so she pleaded with her beloved
Not to leave.

"I don't want him to suffer," she decided
When He seemed to have forgotten them.
And so she invited Him back
With neon green paper, taped to the refrigerator.

"We waited too long, she worried
When her beloved lost his spirit.
And so she called to Him,
With morphine and bittersweet hope.

"Come back," she wailed
When He still didn't come.
And so she suffered, too,
With tears and guilt.

"It's OK to go," she told her beloved
When he seemed to hold on for her sake.
And so she waited,
With love.

It was suddenly silent
When Death finally came.
And so our beloved
Greeted Him as an old friend.

Journal of Palliative Medicine, 23(2), 2000
Doi: 10.1089jpm.2019.0410

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PARENTS' INSIGHTS ON A CHILD'S END OF LIFE

Blyth Lord

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with insights from a panel of bereaved Network parents: Caryn Anthony, Sarah Casey, Oralea Marquardt, Michelle Moon, Brenda Murray, Kerri Padgett, and Jennifer Siedman

Envisioning a child's death is essentially impossible. Wretched and mind-stopping, the prospect may feel like an abandonment of the role as parent, protector, caregiver. Michelle captures the grotesque nature of it: "My greatest fear was that Julianna was going to die, period. When the fear of something is so great that you can't talk about it, even to yourself, it churns around in that subconscious space where it grows and takes on all different kinds of forms. It's hard to describe how horrible it is. You think you can't possibly face it—you'd rather die than face it, but your child needs you."

When my nephew, Hayden, passed away five months prior to my daughter Cameron's death from the same disease, my husband was there in person to support his brother. Thus, he also was able to describe for me Hayden's final days and end of life itself. Charlie's first-hand experience deactivated the worst of my anxiety and dread. This experience, particular to my family, was one of the seeds for Courageous Parents Network: the understanding that it's helpful to address our questions head on, and to look for guidance and answers from others who have been there, too.

What does end of life look like? Can I keep my child comfortable? What are the signs that they are dying? What sort of help will I need? Do I want home or hospital? Which interventions? etc. All of these are healthy questions that indicate a parent's desire to do the best they can for their child in a situation over which they otherwise have no control.

"I had a lot of fear of the unknown around the nitty-gritty, day-to-day symptoms and what Emerson's actual death would look like," Sarah reflects. "These weren't things that I was actively seeking to talk about and I'm not sure that I could have articulated it at the time." Kerri explicitly asked her son's neuro-oncologist about this: "We had this conversation again weeks before Kai's death, when we entered the hospital for the last time. There were no absolutes, no clear answers, but hearing the possibilities with candor left me feeling less fearful of the unknown and more able to focus on the time we had left."

Courageous Parents Network's goal is to equip parents and other close caregivers with honest, but gently delivered, information to help them navigate these unimaginable circumstances. Because the hundreds of voices of CPN are those of other families and their providers, parents see that they too can exist, survive, and even thrive on the other side. It is our strongest belief that information in the face of the dreaded unknown is power.

The CPN unit “Preparing for End of Life” is specifically dedicated to this most difficult topic. Two downloadable guides focus on (1) Preparing for End of Life and (2) What to Expect. Two Guided Pathways—curated digital learning experiences—mirror the guides, incorporating relevant videos and podcasts of parents and providers sharing from their experience. The unit, which includes the videos, podcasts, guides, and Guided Pathways, is available at <https://courageousparentsnetwork.org/topics/preparing-for-end-of-life>.

Now, what do parents want providers and everyone else to understand, so as to help them best support and accompany families? CPN asked our bereaved parents panel three questions: What was your greatest fear about your child’s death?; What do you wish you’d known?; and, What helped you most? The following themes emerged (in no particular order or weight).

Fear that their child would suffer. This is true for all parents but was emphasized by parents who anticipated that their child would die at home with minimal medical support. “I had a lot of fear based around knowing Emerson was going to die, but not knowing at all how or when. I was afraid that whatever happened, I would be alone with her and unable to effectively manage the situation. And I was afraid that because of that, her death would be traumatic and she would suffer,” says Sarah.

Planning for “presence” in the face of uncertainty. Parents desperately want to have a sense for their child’s life expectancy, so that they can be “prepared” for the end. In many cases this is not possible. A child may also recover from near-death moments, making the ultimate moment difficult to recognize. Several parents noted that they struggled with this. Brenda’s son had come back multiple times from being terribly ill: “I wanted someone to say, ‘Brenda, Sam is dying...this is what dying looks like. Forget about everything else. Nothing else matters now. Just lay next to him, hold him, and tell him you love him.’” Caryn notes that “the continual disconnect between the medical team’s problem-solving attitude and Robby’s obvious deterioration fueled confusion and anxiety.” Such a situation is especially unhelpful when the family’s goal is to support the wishes of the child. Caryn continues: “The persistent uncertainty created inherent conflict in how my son understood what was happening to him, and how we managed it together as a family...The most important value we held as we were parenting our son in his last year, was to be honest and present with him, no matter what.”

The burden of decision-making. Parents wrestle with decision-making for the entire illness journey, and this is absolutely the case as they prepare for their child’s death. “My greatest fear is that I would break and not be able to see the decisions that needed to be made with a clear head,” says Jennifer. Oralea’s list is similar: “Will I have the strength to make the right decisions and put William’s needs in front of my own? How can I make end-of-life decisions when I know it means saying goodbye to my son?” Caryn stresses the importance of listening to the wishes of her teenage son as a compass: “As a young adult, Robby had the capacity to understand what was happening and had strong opinions about what he wanted. And knowing that we did everything possible, in the way he needed us to, is what helps us even after he is gone.”

Survival of self. Multiple parents expressed awareness, and concern, that their grief had the potential to interfere with their child's needs—or that the grief would be utterly consuming. “I feared for my life without him while focusing foremost on the relief of his suffering,” shares Kerri. Imagining the other side of the death can feel crippling. Oralea remembers thinking: “How can I possibly live past that moment of his last breath?” She sought out bereaved parents in the patient disease group connected to her son's condition and notes: “Talking to parents who were three, five, ten years out from the time of their child's death, and seeing that they were not broken and that they could laugh again and share memories of their child without being completely destroyed, gave me a sense of peace and hope that I could do the same.”

Respecting signals from the child's body as a path forward. Against this backdrop, several parents felt that their child's body knew what it needed to do. “I worried that there was more I could do, while learning that his body was in charge,” says Kerri. Oralea expresses it this way: “I feel he was ready and that it was he who made the ultimate decision that it was his time to leave us. I did not have to choose it and I did not have to explicitly make many of the decisions that I had dreaded. None of my worries that I had had through the years as I thought about end of life came to fruition. If I had been able to know that and trust that, maybe I would have had a greater sense of calmness.”

The invitation and space to talk about the possibility the child will die. No one wants to talk about this possibility, but it can be liberating and empowering to do so. Kerri says: “With access to both hospital and community-based palliative care, there were many people I could turn to about my fears, worries, and hopes for Kai's life. I contemplated and expressed my thoughts about the possibility of his death from early in diagnosis. While I was hopeful during that time, I spoke often of the dark thoughts in the back of my mind.” Michelle's version of this is especially poignant: “I worried about Julianna's death for years, and I probably knew that she was going to die for at least six months before I could face it. This was the worst time of my life, even worse than her actual death. Admitting it was so incredibly painful, but once I did, it was so much better. In my case, it happened after I finally got myself to a therapist. There was an immense sense of relief, then an odd calmness: I faced it, and it didn't kill me,”

Sadness at leaving the hospital without their child. “It is very hard to just walk out. I wish that I had understood what the process is in the hospital after a child dies. Many of the things that happened were unnerving and I think if I had known I could have prepared,” remembers Jennifer. Kerri adds, “The only regret I have contemplated has been not staying longer with his body after death. I did not know at the time that there was a process of cleaning and dressing the body. I only found this out later in hearing from other parents who participated in this process. I am not sure I would have wanted to do these things myself, but it was hard finding out only after that it was something I could have participated in. There are times I have wished I had stayed longer with his body; however, I recognize that no amount of time would have ever felt enough.”

Impact of the palliative care provider(s). All of these issues exist in that space where palliative care can play a pivotal role. As noted, Kerri's ability to voice her worries and concerns to

palliative care providers is what helped her most. Similarly, Sarah says, “The things that helped me most were having an extremely involved and supportive primary care pediatrician and access to a high quality pediatric palliative care pediatrician, as well as other palliative care providers at the hospital. When I was in those settings, I felt very safe and supported. We had big picture conversations about goals of care, what we hoped for Emerson both in terms of living and dying. This allowed us to make thoughtful decisions that we’ve never regretted or second guessed. I can’t overstate how huge this was.” Jennifer’s son Ben’s palliative care doctor was instrumental in the hospital at the end: “The single most valued resource was our palliative care doctor. When I expressed fear over the rapid pace and my growing sense of being vulnerable and unsure of my decisions, in very concrete terms she reminded me of the things I could control...She gave me clear information on which I could base choices. She helped me find the language to talk with my other children, my spouse, and myself.” (Note: Concern for siblings is chronic; accordingly, the unit includes resources for talking to and supporting the siblings.)

As with all aspects of serious illness and end of life, there is no wrong or right way to proceed or understand. By being aware of what families think and care about, providers can suggest, even articulate, what these parents may be wrestling with—and give them confidence to move forward with minimal regret toward maximal healing. As John O’Donohue expressed so beautifully in this passage from his blessing For Courage:

Close your eyes.
Gather all the kindling
About your heart
To create one spark
That is all you need
To nourish the flame
That will cleanse the dark
Of its weight of festered fear.

Appendix/Sidebar: Courageous Parents Network “Preparing for End of Life” Unit Contents

All CPN materials have been professionally reviewed and edited by pediatric providers.

<https://courageousparentsnetwork.org/topics/preparing-for-end-of-life>.

Part I: Preparing for Your Child’s End of Life

- The Many Experiences of Anticipatory Grief
- Advance Care Planning (ACP): What and Who
- Making Memories and Planning Ahead
- Understanding Your Options Can Help Bring Peace of Mind

Part II: What to Expect

- End of Life: What to Expect
- What Comes After Death: Making Arrangements

- Supporting the Siblings
- Relating to the Care Team
- Bereavement

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CHANGING THE NARRATIVE OF PEDIATRIC DEATH AND DYING: THE STORY OF A BEREAVED PARENT SERVING AS AN END-OF-LIFE DOULA AND HOME FUNERAL GUIDE

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Pathima, mathima

Old Greek saying that we are supposed to learn from what happens to us.

Witnessing my daughter Angelica's final rite of passage reframed the experience of death and dying into a beautiful ritual of love and honor. The preparation for that moment made it possible for the acceptance of its reality to unfold peacefully. We surrounded her with the support she needed for the natural labor of dying. Cheering her on until the last breath at nearly 7 years old was a continuation of tapping into an intuitive energy. Thus, empowering my child to live fully with purpose since her first metabolic crisis at 3 days old. This is when my journey as an End-of-Life Doula (EOLD) began.



Angelica's life-limiting condition required the child-rearing responsibility of guidance to cross the threshold without fear. This pragmatic perspective recognized that my child needed to feel safe and understood. A holistic approach to nurturing her well-being powered our family through carrying the burden of anticipatory grief. There was an ever-present fear that today may be the last time we embrace her. I learned that control is what we make of it. Dignity and resilience provided the foundation for forging ahead into the path of unknowns towards a certain ending.

Children experience life with a wisdom that they may not be able to articulate. That is when holding space without judgement allows them to process and share how they feel and what they need in their own timing. Listening to what my child wanted did not always resonate with what I had hoped for. Caregiving is a sacrifice to personal thoughts of what should be.

Reflecting on the proving grounds of following my own child's wishes gave incredible insight into the delicate balance of diplomacy. Angelica rejected the idea of returning to invasive procedures after a harrowing final round of medical treatments. Subsequent doubt and confusion that caused my own intuition to waver came from outside pressure to consider saving her. I explained to her the choices and possible outcomes. She understood quality of life

and the implications of each scenario. The concise response of my primarily nonverbal child obligated me to honor the final phase. Her clear “NO” and knit eyebrows signaled the invitation of hospice care. Curative care was no longer an option for Angelica.

Angelica appeared well and continued daily activities with resilience in those final months. Changes appeared slowly at first, which frustrated her, prompting anger. A shift in parenting happened when I had to witness my child’s decline. She was dying and wanted companionship through new feelings. The distinct memory of sitting quietly beside her after a tantrum compelled me to instinctively hold space. Her anger subsided and she looked at me with such sadness. We sat together in silence with my arm around her. Then I spoke to her in Greek which she preferred for moments like this. “*Ela mou*, Mommy knows you are sad because you don’t feel good. You will not get better. I am sorry *agape mou*. Mommy will help.” This exchange was a pivotal experience as she approached the time of transition.

Parents need the same validation of acknowledgment for what is normal for them. They follow a similar route knowing that it will continue without the physical presence of their beloved child. The EOLD serves as a participant observer that provides non-medical and non-judgmental support for families to help them control their own narrative. Being present for what is most important to them involves coaching for what is to come. The EOLD advocates on behalf of their wishes and needs when strength is depleted or the focus elsewhere.

Becoming an end-of-life practitioner seamlessly blended into surviving as a bereaved parent. There was an undeniable force that gravitated me to this calling. The doula model of care encompasses the essence of palliative care to rely on intuition, poise, and empathy. Our role is to empower families by being proactive, creative, and solution oriented. Facilitating difficult conversations confronts the complexity of relationships and situations to connect with what is best for the child. An EOLD works together with other professionals by sharing our observations and expertise, bringing something different to the table.

The desire to keep Angelica’s body home after death was deeply rooted in my Greek heritage and her upbringing. I promised my daughter that we would take care of her until the end, meaning the disposition. Home funerals generally do not require embalming and encourage family participation for preparing the body regardless of disposition. Activating our family’s circle of support while she was actively dying allowed us to create a sacred space to give her full permission to let go. Angelica’s breathing plateaued into a delayed rhythmic pattern while she heard what a great job she was doing. The moment she crossed over we were prepared.

The EOLD skill set may include after death care as a Home Funeral Guide (HFG). Our family consulted an HFG that instructed us on how to take care of the body. That meeting was incredibly valuable and reassuring that we were capable. Our HFG reminded us that we could spend time with the body before the preparation. She also connected us with a local funeral director that would assist the process as Michigan law requires it. My own loving hands cared for the child that I had carried in the womb, enabling me to process the grief through the shock of entering a new reality.

The hesitation to share funeral plans with our families, healthcare providers, and hospital staff resulted from guilt of possibly declining life-saving measures. I had an Eastern Orthodox prayer book in Angelica's hospital bag. A laminated copy of the Resurrection icon marked the page of prayers for the dying. I wanted to be calm if she coded and to read the prayers over the body before calling the priest, knowing we would have to negotiate her transport home.

Families inquiring about a home funeral may change their mind or circumstances may dictate otherwise. That is established at the initial consult. It is our ethical responsibility to present choices and alternative scenarios. Especially for those that may not have social support or the logistic feasibility. Losses from early pregnancy, medical complications, or trauma may necessitate alternative considerations for the body preparation and vigil arrangement. Plans need to be flexible to accommodate fluid situations.

There was an intense confusion about how to include end-of-life wishes in Angelica's goals of care when curative measures appeared less viable in the last year of hospitalizations. It was refreshing to openly talk to those that would listen to my concerns for the dying process and after-death care. I researched during respite times about code status, hospice care, details of the dying process, and funeral planning. It felt like betrayal when browsing pine caskets on the internet while Angelica napped. This is not a criticism to standard protocols and practice. However, it offers a glimpse of the unnecessary anxiety and disconnect that may affect an equally important time for our children.

During an initial consult, the family story abundant with nuances, guides the conversation when we meet for the first time. The goal is to get a sense of their perspective and expectations. It also sets a tone for maintaining boundaries and emphasizes the importance of listening to them. They are safe and information is confidential unless given permission to share on their behalf. I can refer families to colleagues if we are not a good match and other organizations if their requests are outside of my scope of practice. A support plan is then created that may alter, adapting to changes. EOLD collectives such as the one I am part of assure back-up support or collaboration.

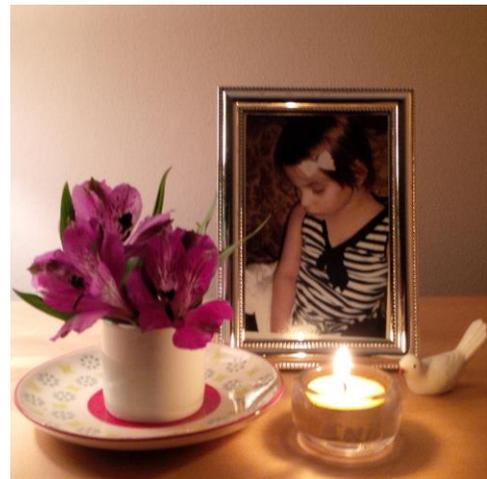
Journeying with a family from the diagnosis to after death reinforces the trusted companionship developed over time that fosters a continuity of care. This is an ideal outcome but not necessary. We can help at any stage, for various needs, and help families connect with how to honor their grief. Grief support is available as a separate service as well. Providing resources, creating memorial projects, teaching about ritual, and checking-in are common practice.

We must enter sacred space grounded and ready to take in the energy of the environment to optimize support. My first pediatric home funeral consult for 10-month-old baby Evey was one of crisis mode. The palliative care team diligently worked throughout the day to reach someone to help a newly bereaved mother take her baby home for a vigil before cremation. It was divine timing in how we connected.

The strength of a mother's grief and love welcomed me into the hospital room. There was an instant collaboration with staff. Our coordinated effort to navigate through policy, protocols, and partnerships gave precious time to a mourning mother devoted to nurturing her child the way she needed to. The family had a lovely four-day home vigil. They were able to spend time and make memories with Evey in familiar surroundings before the final farewell to her physical presence. Evey's story initiated a new dialogue about EOLD support, home funeral protocols, and the hospital body release policy.

Then came a first official referral from a Peds Palliative Care social worker. The family awaiting the arrival of baby Oliver wanted to bring his body home. Connecting with Oliver's mother throughout the pregnancy gave her the support to honor the inner wisdom of parenthood. My involvement as an EOLD was activated as needed. There were circumstances that changed the original plan for a direct transport to their home. However, conversations prior to his birth led to a seamless transition to an alternative scenario. Oliver's family welcomed him with reassurance that their wishes would be fulfilled. His body was held and loved by family in an intimate setting before the funeral. Oliver's story was used in a training to help EOLD students learn about the unique aspects and considerations of perinatal support.

I strongly feel my daughter's spirit in this work. Repurposing lessons learned from caring for her influences how I speak my truth and inspire others to find their own voice. As End-of-Life Doulas, it is our professional purpose to network, form partnerships, and collaborate with mainstream systems to complement existing services in the palliative and death care continuums. Advocacy parallels activism to validate and normalize the needs of the dying and their loved ones. A great love and respect for my child loss tribe and other dedicated end-of-life professionals is a beautiful relationship of reciprocity that naturally contributes to a positive approach to death, dying, and bereavement. Our collective motivation to seek understanding for achieving a meaningful final rite of passage is the process for a narrative of change.



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KIDS & DEATH AND DYING: A REFLECTION

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I believe it was Art Linkletter who coined the phrase, “Kids say the darndest things.” However, in reflecting on death and dying and how it impacts children, it’s really more about “Kids ask the darndest things.” Unfortunately, as untrained “mere mortals,” we’re often not equipped to know what or how to answer those questions. We do our best; sometimes we’re heroes and sometimes we’re not—maybe doing even more harm, but the important thing is that we try. Yes, these forgotten mourners often have lots and lots of questions and we owe it to them to try to address them, especially in some of their first encounters with death and dying.

As I reflected on the instances of my own, and my sister’s, children’s first brushes with death and dying, several scenes vividly play in my mind like a movie reel. The situations were complicated (aren’t they always?) and I felt I was navigating them with these kids on my own as no other adults were accessible to them. So, for better or worse, here’s what happened and how these situations played out.

Grandma Moira’s Viewing

My children were young, about 9 and 3 1/2 when their first grandparent died from cancer. It was a difficult loss for all of us as she was beloved, but my father-in-law was particularly reeling. Life wasn’t supposed to happen this way; she wasn’t supposed to die first.

As we entered the funeral home for the pre-family-only viewing of her body, I wasn’t sure what to expect. Yes, I had decided to bring my boys in their little suit coats and ties to pay respect to this woman they also loved. No, I was not going to shield them from this. No, they weren’t too young. As we approached the casket, their eyes were filled with wide-eyed wonder. I could only imagine what was going through their minds. Then, the questions started...what did they do to her? Why isn’t she moving? How come we can only see half of her? Is she wearing nylons? Did they put her shoes on? DID THEY CUT OFF HER LEGS?

This last question took me completely off guard, but then I realized this casket, half open, must look like one of those magicians who saws his assistant in half, and they were probably wondering if Grandma Moira had been sawed in half. I encouraged them to touch her, feel how hard she was, explain what I could in child-like language about what had been done to her and why. Then, it became clear the leg question wasn’t going away, so I opened the bottom half of the casket—yes, she thankfully had nylons, shoes and legs, all intact. As my children continued to explore her, very respectfully, with their hands, my father-in-law returned to the viewing room and rushed to the casket to ask what we were doing. He pushed my boys away and closed the bottom half of the casket and sharply reprimanded me and them, saying, “Show some respect for the dead.”

While this scene to my father-in-law seemed disrespectful, it could not have been more tender and loving as my boys said good-bye to this loving Grandmother. I was glad we'd gotten as far as we did and that I could address their most burning questions about her dying and this ritual of viewing her body (and that yes, she got to keep her legs). Nevertheless, I was saddened by the chastisement they received for just being kids trying to understand death and dying in a way that was familiar to them—through their sense of touch. Their need to understand was overshadowed by a grandfather's need to control what he could in a situation that he had not been able to write the ending he had wanted for his wife of so many years. It also became about his issues with death and dying and how he himself was not coping. We all could have learned from these loving grandkids that day.

Grandma Mary's Viewing

When Grandma #2 died, it had been a 9-year-long, slow decline due to early-onset Alzheimer's which started at age 59. My kids and nephews really only knew Grandma Mary from visits to her various nursing homes, given how young they were when she got diagnosed.

During those years, while my Mom had always prided herself on keeping herself looking good, as this disease tore through her, some of her "beautifying" routines like dyeing her hair just had to fall by the wayside. The act of putting her through all that when she didn't understand what they were doing to her just didn't seem fair to her anymore, so I convinced my Dad to let us stop and let her hair grow white.

However, after she died, my Dad handed me a photo as I was heading to the funeral home to bring her clothes/shoes to dress her in for the viewing. He said, in no uncertain terms, "I want her to look just like this." The problem was, the photo was of her from about 20 years before with her dyed and styled hair. He was so broken after my mom's passing that all I could say was I'd ask. Luckily, I found a very willing accomplice in the funeral home's mortician who said he'd try if I could bring him 3 boxes of her color—and so I did and prayed that my Dad would get his wish.

A few days later, as we entered the viewing room, to my surprise, the mortician had weaved his magic: my Mom indeed looked just like the photo, which brought tears to my Dad's eyes. However, the grandchildren were another story. As they approached the casket, they looked and looked and one finally turned around and commented that we must be in the wrong room—that this wasn't Grandma. You see, this looked nothing like the Grandma they had visited for years as small children. They urged me to take them to another room to find her, as clearly this woman with medium ash blonde hair (and not white hair), make-up, etc., was an imposter and clearly NOT their Grandma.

How foolish I was to not anticipate this reaction from them. In my quest to honor my Dad's needs, it never occurred to me that the grandkids may not recognize her. So, again, there was much time spent at the casket exploring and asking questions. My boys and my nephews were a little older now (6 and 12), so the questions were more technical—what EXACTLY do they put

into her to make her so hard? What do they do with all her insides? Does she still have eyes? Why do they put make-up on if she's not going anywhere and why do they put on so much of it (they were looking really closely!). While I could have answered some of the questions, I thought it best to call in reinforcements as some/much of this was out of my league, so we went to the desk to see if the mortician was still in the building and if he'd mind coming to answer a few questions. He did and was a great sport about explaining the embalming process in ways I never could. In this case, I was glad to again be able to solve some of these death and dying mysteries, for my kids and my nephews, with the help of a professional. My nephews would experience the death of their mom 10 months later, so addressing some of this laid the foundation for some higher level of understanding and acceptance when she died the following year.

Aunt Moe's Death at Home

My younger sister died at my home under hospice care when she was only 44 years old, leaving behind three boys, the youngest who was only 4 1/2. And while she had sent her own children away to not return before she died because it was too hard for *her* to let go and transition with them here (a regret I carry to this day), my children were still living in the house with my husband and me. At the time, they were 13, 7 and 1 ½ years of age.

On the last day of her life, as she was actively dying, my husband got my boys up and dressed, fed, and ready for school. My husband and I had decided to send them to school knowing what the day might bring. My sister and I also had a pact that there would be "No little people" in the house when she died. Before they left for school, I asked them if they wanted to come in and say good-bye to Aunt Moe. My middle son, 7 at the time, came to the doorway of my bedroom where my sister lay comatose in a hospital bed with some labored breaths, surrounded by her husband, my Dad, and me. At the sight of her he froze and would not take one step further into the room. The fear on his face was palpable. He then turned and without saying a word, headed down the stairs never to see her alive again.

My oldest son, then 13, quietly just whispered from the doorway, "Good-bye Aunt Moe, love you." He too, did not want to enter the room. Intuitively, I suspect they both knew she was dying and that this was different from a funeral home viewing where the dying part was over. This was active, and real, and happening in real time in their own house, and to them, it was seemingly overwhelming. On this day, there were no questions, only fear and sadness.

So, what were the "lessons learned" from my personal reflections on my children and nephews' experiences with death and dying? It was reminded that as adults supporting a child(ren) through someone they know who is dying, or has already died, we need to:

- **Meet these children where they are, wherever that may be.** Importantly, if they're lagging where the situation is heading, frame it for them with a time period that they'll understand so they don't lose precious time not doing or saying what's important to them before it's too late.

- **Follow their lead; they get to drive where this heads for them**—what they can take in and what they can't. We cannot force our views or what we think they should be doing or feeling, upon them. This is their mourning and grief journey, not ours.
- **Let them ask questions until their curiosities are satisfied.** We know the literature teaches us that what they imagine is, or has already, happened, is often far worse than maybe the reality of the situation. Do your best to answer their questions and if you don't know, tell them that. "I don't know" is an acceptable response, but also an invitation to engage the child in what they might be thinking. If it's an important question, try to find an answer or enlist someone more experienced on the topic to help. If they need "show and tell" and it's not going to upset anyone (or maybe even if it is), let them look, touch, etc. Like puppies, this is how they explore and make sense of their world and difficult subjects within their world.
- **Let them be part of the process—don't shield them from death or dying, but instead, engage them into participating** in what's happening so they get more comfortable with it (and it creates great memories for them after the person is gone).
- **And when else fails, call in the cavalry.** There is nothing wrong with asking for help. If you're struggling yourself, find someone who can take on this role for the child(ren)—a friend, pastor, other family relative, or look for an expert (remember the mortician?).

While these seem like things any supportive adult would do to help a child through a journey of a relative or friend who is dying or has died, it doesn't always happen this way. Life gets in the way---we're swept up in our own grief, we are afraid to take this on, we don't have any of the answers and feel horribly unqualified, we think we may make things worse, etc. However, it's important children feel "seen" and "heard" during these times, so finding the courage to be there and simply asking if they have any questions may be a first step to their healing to the other side of this experience. Remember, we don't know what they're thinking unless we ask. And in the end, sometimes helping a child process through a death and dying experience can be as simple as lifting the bottom half of the casket to show them that Grandma still has her legs. You, and the children you will have the privilege to support, can do hard things. You've got this.

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ARTIFICIAL NUTRITION AT THE END OF A CHILD'S LIFE

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When a child is nearing end of life, managing nutrition as well as promoting comfort can be challenging. Artificial nutrition and hydration (ANH) are some of the tools that might be involved at end of life (EOL). Because of the association of “feeding” with comfort, nurturing, and love of the child, decisions about use of ANH can be particularly difficult.

What is ANH?

ANH is nutrition that is not taken orally. ANH can be provided enterally through nasogastric, jejunal, and gastrostomy tubes, and intravenously (total parenteral nutrition). ANH is frequently used when oral nutrition is not possible or sufficient either temporarily or permanently. In this case, ANH may be beneficial and support possible goals of cure or prolonging life. But remember: *Above all, do no harm*. What if there is no longer a benefit or if the burdens outweigh the benefits? At the end of the child's life, does the provision of ANH meet the goal of providing comfort? Or does ANH prolong the dying process and increase discomfort?

When might ANH be initiated at end of life?

As death nears, the appetite naturally decreases, and caloric demands are reduced. If the child is thirsty or hungry and can safely eat or drink, he/she should be offered oral fluid and nutrition for comfort. If the child expresses hunger but cannot safely or comfortably be orally fed, ANH (such as through a nasogastric tube) could be considered to improve comfort and decrease hunger and thirst. Total parenteral nutrition requires a central venous line and has more complications but has, on rare occasions, been started if benefits are perceived to outweigh the risks and burdens. If a trial of ANH is considered, clarify the goals, potential benefits, and potential risks and complications. Also clarify the signs that the goals are not met, and when the trial should stop.

Managing ANH at end of life

There has been no proven benefit and there may be harm in using ANH at end of life. As the child is dying, the body moves less, has a lower temperature, and spends less energy. If the intake is continued unchanged, overfeeding and symptoms will likely result. Hydration does not seem to improve quality of life within days to weeks of death. If intravenous hydration is continued, expect that fluid needs would be about 50-75% of the usual.

Potential burdens of continuing ANH:

- Discomfort

- Bloating and abdominal distention
- Ileus, nausea, vomiting, and diarrhea
- Bleeding, infection, displacement of feeding tubes
- Coughing
- Increased respiratory secretions, pulmonary edema and dyspnea
- Infection with intravenous catheter
- Overhydration contributing to respiratory secretions, pulmonary edema, congestive heart failure, and fluid retention
- Prolonging the dying process

The health care team should evaluate to ensure that any treatable causes of the above symptoms are managed.

Potential benefits of decreasing, withdrawing, or withholding ANH:

- Minimize above symptoms
- Minimize risk of sepsis from central lines and complications from G tubes
- Easier to care for at home
- Minimize blood draws
- Enhance wellbeing through ketosis and endorphin production

If the above signs and symptoms occur and are not treatable, discontinuing (or at least reducing) ANH should be discussed. *Stopping or reducing the ANH does not mean stopping care or caring.* Continued assessment and management with the medical and palliative/hospice teams remains vital.

What is our understanding of what might happen when nutrition and fluids are stopped? Frader (2007) frames this nicely. The minimally responsive child is unlikely to experience thirst or hunger. In more aware children, hunger may last up to 24 hours and thirst possibly lasting up to 3 days. It is thought that the ketosis resulting from decreasing fluid and nutrition results in a mild euphoria and decreased thirst and hunger. While these data are based primarily on research in adults, parent reports in small numbers of children are consistent. Analgesics and sedatives should be used as needed to treat any discomfort. Sucking on a finger or moist swab may sooth some children. Skin and mouth care for dry mouth are frequently needed. The care team can give the parents some idea of the trajectory of the dying process, but trying to predict the timeline is challenging. (There have been case reports of babies surviving for 4 weeks.) Palliative/hospice care and communication with the child (if able) and family should likely intensify. Attention to psychosocial and spiritual needs of the child, parents, siblings, and the rest of the family is imperative. Providers can ensure that they will be available to compassionately address any distress in the child and family. It is also important to support members of the health care team.

Discussing stopping or reducing ANH with parents at the end of the child's life

While the site of the discussion does not seem to be important, readiness of the parents and consistency of the message from health care providers impacts on their perception of the discussion. *Words matter!* As the word “feeding” emotionally connotes comfort, use the words “artificial” or “medical” to characterize nutrition or fluids not given orally. It is important to review the goals of care, which at end of life generally include comfort, minimizing symptoms, and optimizing time with loved ones. Does provision of ANH meet these goals? If so, consider reducing volume and be attentive to symptoms of feeding complications. If not, consider discontinuing ANH and focus on symptom management. This is one of the things that can improve comfort at the end of the child's life. The personal experience, religion, and personal values will likely influence the parents' decision. Because parents expressed distress when getting conflicting recommendations from team members, a good strategy is to meet with the health care team members to review the issues and plan before discussing discontinuing the ANH with the family. Any dissenting opinions should be resolved before discussions with parents so that the team can be consistent. Some organizations have policies for a health care provider to opt out on grounds of conscience or religion. Expect and respect different opinions.

For those parents who accept forgoing ANH as part of palliation, the decision is often supported by a perception of the child's poor quality of life, often including feeding intolerance. The death is described by many parents as peaceful and comfortable, especially if the dying process was similar to that described by the palliative care/hospice team. In one small study (Rapoport et. al.), parents did not express regret, and all were satisfied with their decision to forego ANH.

Is stopping ANH OK???

In a June 2018 comment on the American Academy of Pediatrics Pediatric Palliative Care listserv (PPCAAP@listserv.aap.org), David Steinhorn, MD, framed the question this way: “What is the least bad of all the bad options, when there is no good option on the table?”

It is important to emphasize that withholding or withdrawing ANH as part of palliative care is medically, ethically, and legally equivalent to withholding or withdrawing other non-beneficial life sustaining treatments such as artificial ventilation, medications, or surgery. It is NOT euthanasia. Death occurs from the underlying condition. As with discontinuing other medical treatments that are no longer helpful, withdrawing medically provided fluids and nutrition is an ethically permissible option when the goals are not met, and/or the burdens of the treatment outweigh the benefits. While withdrawing or withholding ANH is morally permissible, it is not morally required. A bioethics consultation can be very informative in all cases and is strongly advised in any difficult case where controversy arises.

Decreasing, withdrawing, or withholding ANH is a medically, ethically, and legally available option and should be considered as part of palliative care at end of life if indicated. Parents and the medical team can be assured that this is an available option to further comfort at end of life. However, because of emotional associations with “feeding,” the shared decision making can be stressful.

Resources

Andersen A-K, Burke K, Bendle, Koh M, McCulloch R, Breen M. Artificial nutrition and hydration for children and young people towards end of life: Consensus guidelines across four specialist paediatric palliative care centres. *BMJ Supportive & Palliative Care*. Published Online First: 19 October 2019. doi: 10.1136/bmjspcare-2019-001909

Canfield KN, Frader JE. Forgoing artificial nutrition and hydration: What to make of parents' views. *Pediatrics* 2013;131:993-994.

Diekema DS, Botkin JR, The American Academy of Pediatrics Committee on Bioethics. Clinical Report – Forgoing Medically Provider Nutrition and Hydration in Children. *Pediatrics* 124(2);2009:813-822

Drake R, Frost J, Collins JJ. The symptoms of dying children. *J Symptom Manage* 2003;26:594-603. Symptoms of children dying in the hospital.

Frader JE. Discontinuing artificial fluids and nutrition: Discussions with children's families. *Hastings Cent Rep*. Jan-Feb 2007;37(1),1

Hauer J. Feeding intolerance in children with severe impairment of the central nervous system: Strategies for treatment and prevention. *Children* 2018; 5(1) Open access <https://doi.org/10.3390/children5010001>

Hauer J. Understanding nutritional needs with feeding tubes throughout illness and at the end of life. *Courageous Parents' Network* 3/18. Open access <https://api.courageousparentsnetwork.org/app/uploads/2018/03/CPN-Nutritional-Needs.pdf>

Keeler A. Artificial hydration in pediatric end-of-life care. *Virtual Mentor*. 2010;12(7):558-563 <https://journalofethics.ama-assn.org/article/artificial-hydration-pediatric-end-life-care/2010-07>

National Hospice and Palliative Care Organization. *Commentary and Position Statement on Artificial Nutrition and Hydration*. 9/2010. https://www.nhpco.org/wp-content/uploads/2019/04/ANH_Statement_Commentary.pdf

Rapoport A, Shaheed J, Newman C, Rugg M, Steele R. Parental perceptions of forgoing artificial nutrition and hydration during end-of-life care. *Pediatrics* 2013;131:861-869

Tsai E; Canadian Paediatric Society, Bioethics Committee. Withholding and withdrawing artificial nutrition and hydration. *Paediatrics & Child Health* 2011;16(4);241-242. (reaffirmed 2/2018)

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ASSESSMENT IN MEMORY AND MEANING MAKING: INTENTIONALITY AS A CHILD DIES

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One of the questions that often surfaces when we know that a child is dying, or has died, is whether or not to offer the child and/or their loved ones the opportunity to engage in what many refer to as "memory making." Although it certainly can be important to engage in, these processes are far from benign. It is important that the conversation, as well as the activities themselves, be afforded proper assessment and intentionality. In the following conversation, we will explore the concepts of memory making, legacy making, and meaning making. We will also discuss how, when, and if we approach patients and/or their loved ones in this regard. Following is a conversation between Hania Thomas-Adams, MA, Certified Child Life Specialist, and Marta Friedman, LCSW, ACHP-SW, JD, Palliative Care Social Worker/Bereavement Coordinator, UCSF Benioff Children's Hospital Oakland.

MF:

I know that both of us are often asked to step in with families when a child is dying or has already died. Typically, it is in response to a request from staff for "memory making." What are your first steps when you get a request?

HTA:

The process of creating legacy items with a family is a deeply profound and sacred one, and I personally do not believe it should be done unless there is a therapeutic relationship anchoring the participants. Therefore, this is not an activity that should be performed in haste, generically prescribed, or initiated for the sake of having done so. This is a process that we sometimes have the great honor of witnessing and walking through with families, and for me the first step is establishing a relationship based on trust. I would begin by visiting with the family and attempting to gain a deeper understanding of who they are, who their child is, and what might be meaningful and healing for them during this time of unimaginable pain.

MF:

I echo your sentiments that these moments are profound and deeply impactful. There is nothing rote about the notions of legacy and remembrances, nor about the role(s) that providers hold. I would add to this that there are occasions when we do not have the latitude of time to develop our relationships in a more expansive way, where the situation is more urgent or emergent, and where we have to act quickly. These moments can be awkward, if not truly challenging. Yet, we can find creative ways to define what is a therapeutic and deep connection. During these times, and always, I remind myself that this child's death is final, we are not the immediately bereaved, we are not in the same state of shock, and we are, in fact, in the position to guide those who are. This is not to say, of course, that we are unfeeling, nor that we do not have our own responses to what we are witnessing.

Particularly in the setting of miscarriage or stillbirth—which often receives limited visibility and regard—and for the newborns and infants, these might be the sole moments for creating memorials and legacy beyond, of course, that which has begun when the family has learned of the pregnancy. Added to that is how the family's dreams and visions of what their lives were going to be like with this child are forever altered. The narrative changes inherently, including the looking back.

HTA:

Yes, the age of the child plays a significant role in my decision to initiate the memory making process with families. Tangible items like hand molds and footprints can be seen as part of the process of *legacy building*—doing, saying, and/or creating things to leave behind after one's death, often in accordance with a particular narrative of who that person was and how they will be remembered. If the dying child is an infant, the tangible items made at the bedside just prior to or following death can have the distinction of being the only tokens of that child's life that their family will have to hold onto after they die. The memories made at the bedside are perhaps the only memories of that living child and a large percentage of that child's story; thus, they take on particular significance. A therapeutic relationship and atmosphere of trust can be built even when time is of the essence and I would prioritize this process. An older child has been living their legacy every day of their life and is more likely to have created many tangible memories over the course of that life. For this reason, I would be more cautious initiating the memory making process in the case of an older child's sudden death, particularly if the child has already died.

In your work, are there similar distinctions that you make based on situational, child, or family factors? What other factors might influence your process?

MF:

Yes. These factors inform how I sit with patients and families. I also consider who is available to support the child and the bereaved, and what their internal resources might be. I am mindful of how the act of engaging in memory making or legacy building can be part of either anticipatory grief and/or grief in process. It is striking how much the very suggestion of engaging in these activities invokes a new level of acknowledgment and, for some, self-reported acceptance.

Although, I never expect acceptance per se. These acts can be immensely healing, therapeutic if you like. For some, they become the first moments of new rituals and traditions.

I am thinking now of a five-month-old child who died in our PICU. Before he took his last breath, the Child Life Specialist (CLS) in the unit offered his mother a number of different ways to engage in memory making. Mom sat at his bedside and began to cut several locks of his hair. She then took each lock, wet it, and then slowly, slowly curled it around her finger before tying it with a ribbon. As she did so, she quietly sang to him, the same song, over and over. This ritual, her connection, the very movements she engaged in, were of her own making. The CLS provided the tools. Mom provided the meaning and the intent. Similarly, for the child engaged in their own legacy making, it can be one of the most intimate elements of their good-bye; in their own words, and by their own hand.

Have you ever made an affirmative decision not to offer the opportunity of memory making? If yes, what has been behind that decision?

HTA:

I remember an eight-year-old girl who came to our PICU after a very sudden and catastrophic brain bleed. She had arrived late in the night and despite hours of attempts to save her, she died early the next morning. I met her parents very soon thereafter, and it was clear to me that these parents were in a near-paralysis state of shock. They had spent the night watching their daughter's body be relentlessly worked on, manipulated, and filled with tubes, and now stood in the aftermath having to face her death. These parents were barely communicative and rigid with grief, and because of the suddenness of the child's death they were also facing a limited time with her body before it would be claimed by the coroner. I was asked by nursing staff to consider initiating the handprint making process, and yet as I knelt before these parents, I strongly sensed that this was not the appropriate course of action. They were unable to make decisions and had barely touched their daughter yet seemed desperate to do so. From what they had told me, this was a child who had lived a vibrant, full life and left a legacy of photographs, videos, and artwork. It struck me that what these parents needed was time with their daughter, and since time was limited what I ended up trying to create for them was dedicated time. There happened to be an unoccupied space in the PICU next to this child's bedside, and the child's nurse and I made an impromptu king-sized bed by placing the beds next to each other and filling the gap with blankets. We unhooked and removed every piece of medical equipment that we could, situated the child's body in the center of the bed, and closed off the area with curtains. Within several minutes her parents had moved from the spot they had been in for hours and gotten into bed on either side of their daughter. Their remaining time in the PICU was spent holding their child and each other, getting her changed into clean clothes, and brushing her hair into pigtails. These were the last moments they would have with their daughter. It wasn't handprint making, but it was memory making and it was sacred.

You mentioned instances in which a child is engaged in their own legacy making. Tell me more about your experience with this.

MF:

I'm actually going to punt to you to share an experience, as I recall the time you spent with M. What I do want to mention, however, is what can come about as the converse—when a child who is nearing the end of their life does not have the opportunity to engage in telling their story or creating part of their family's forever narrative (assuming they would want to do so, and are able to do so). We understand that even very young children know when they are quite ill. Although their understanding and expression might be very different based on their age, cognitive status, developmental differences, functional status, emotional status, and so forth. This often ties in to issues surrounding disclosure—of both diagnosis and prognosis, perhaps mutual pretense—parent/caregiver desire to protect their child by not disclosing what they know, child's desire to protect their parent by not disclosing what they know, cultural, spiritual, or religious systems of belief and practice, and the fear of naming something that might signal to others the giving up of hope or the possibility of a miracle. I have seen many parents/caregivers struggle, painfully so, with whether and how much to disclose. When they choose not to, I know that for many providers this is difficult to witness and, frequently, take part in—in part because it seemingly obviates the child's opportunity for closure, or saying good-bye, bequeathing their treasures, or informing their legacy. There is no right or wrong, better or worse. We trust that parents know their child best. We also have the benefit, again, of not being immersed in the depth of their pain and can offer guidance and a different perspective. Yet, we can acknowledge that, at times, this leads to moral distress—truly for all involved. How the distress and disease present, of course, is different for providers than it is for the parent/caregivers.

Please share, if you will, your experience working with M.

HTA:

M was a spunky, loyal, emotionally-astute adolescent that I worked with for about a year and a half leading up to her death from an aggressive and untreatable cancer. Throughout the time that I knew them, M and her family professed and maintained a steady refusal to discuss or otherwise acknowledge her terminal diagnosis. This seemingly originated with her mother, who stated that she did not want to tell M that she was dying due to a fear of taking away her hope and hastening her death. This lack of open dialogue and disclosure created an overarching atmosphere of mutual pretense and carefully avoided themes, in which M was an active participant. Her providers, myself included, found ourselves struggling to honor the family's wishes while supporting this young woman emotionally and bearing witness to her dying process. In the end, I was able to facilitate M's process of planning, creating, and leaving her own legacy through a series of purposeful creative outlets such as art making, scrapbooking, and making gifts for her family. These were media that M was already comfortable with and that brought her joy. Throughout our time together they also provided a language through which she was able to plan for her death and say goodbye. I also taught M to write poetry, and she used her poems to highlight the parts of her life that she loved most while metaphorically exploring her illness and her mortality. Her terminal diagnosis remained unspoken until her death, yet these therapeutic outlets gave M the opportunity to address it without directly talking about it. When her mother became pregnant, M wrote a letter to the unborn baby in

which she thanked her and gave her advice as an older sister. It was one of the last projects she completed prior to her death. Months later I had the opportunity to visit the family again and noticed M's framed letter and photograph hanging over her sister's crib. Though the two never met, M's legacy was part of her sister's life from the moment she was born.

Each child, each family, and each encounter are so unique. Is there anything about the memory making/legacy building process that you consider to be universal?

MF:

That's a stellar question! I hesitate in some ways to speak in terms of universality, mostly because I want to avoid the pitfalls of the "same, same." Having said that, when I think about dying and death in general, I think about how this is the common denominator that links every human being with all others. With that is the realization that we all are somewhere on the continuum of birth to death and can or might or will address the issues of legacy and meaning in our own lives. Dying and death is something that falls outside the bounds of the us/them, as it is by nature "we." In acknowledging the common denominator of death comes to all, I do believe it is important to be mindful of who we are when we walk in the room. How well do we know ourselves, our edges, our own triggers, and how conscientious are we of what we bring into the room? I often begin teaching opportunities by encouraging others to "know thyself," as a work-in-progress (a life-long work-in-progress at that!), and how this informs our presence and our role in joining others through the process of memory making/legacy building. And with *that*, the ever-present words of caution to maintain a sense of curious and respectful boundaries, giving latitude for the process to unfold as the grievers direct.

What about you? Anything you consider universal? Or any last words you would like to share?

HTA:

Yes, death is universal. So too are the human capacities to love, to mourn, and to impact the lives and stories of others. Every child and family I have ever worked with at the end of life has been unique, yet at the center of each family has been love and connection. Every child has been fiercely and beautifully alive right up until the moment of their death, and each family member has faced that death with the deepest kind of sorrow that only comes through the deepest kind of love. When families have talked about their children with me, shown me pictures, or told their stories, those tributes have each contained that family's ringing truth: This child was the best child on Earth. I have never loved anything more. My sister was so, so funny. My brother was my best friend. I don't know how to go on without her. I will carry him with me forever. The legacies of these children do live on in their family, and it is such an incredible honor to walk alongside them and witness that legacy being built for a brief time. I hope they know that their children's legacies live on in my memory as well, and I carry each one of them carefully in my heart.

HTA & MF:

We remember.

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MEMORIES & MILESTONES: THE IMPORTANCE OF INTANGIBLE LEGACY BUILDING

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When you die, what do you want people to remember about you? What is your current living legacy? As a Certified Child Life Specialist (CCLS), I have significant experience working with patients and families. In this work I have utilized both tangible and intangible aspects of legacy building and memory making.

Typically, these are thought of in the context of end-of-life and postmortem activities. Practitioners in adult palliative care historically have defined “legacy making activities” as tangible products created in family contexts specifically to prepare for the end of life (Allen, Hilgeman, Ege, Shuster, & Burgio, 2008). These are often described as being tangible items that “result in a product that can be enjoyed by family and friends prior to and after the individual’s death,” such as plaster molds, ink print pendants, and other tangible keepsakes families can have once a person has died (p. 1031). However, I urge professionals within palliative care and hospice services to think beyond that definition.

Beyond those tangible keepsakes, we have a duty to focus on the wishes of the patient and family in order to consider what favorite activities or even milestones are of importance to them (Staudt, 2013 p.1072). I urge professionals to shift to a living legacy perspective which is described as “A lifelong process of co-creation between oneself and others as we create, internalize, and represent our memories in meaningful ways—regardless of long-term prognosis. In this way, legacies are personal and relational summations of our unique histories, current activities, and hopes for the future” (Boles, 2014, p. 43). The living legacy perspective speaks to a renewed sense of honoring the life, living wishes, and intangible legacy building opportunities we can create for the patients and families we serve.

M., an 18-year-old male with a hospice diagnosis of Down Syndrome, heart failure, and other complex medical conditions, was a sweet, joyful boy with a unique laugh who had been on our hospice service for over a year. M. and his family were focused on a concurrent care model of pediatric hospice. M. was full of life and his unique laughter was abundant in our session. Typically, our sessions focused on emotional expression, medical play, and therapeutic play as he was homebound and craved social interaction.

During my visits in M’s home I was able to meet his home-based speech and occupational therapists and collaborate on ways we could increase his use of words and ability to verbalize his needs, wants, and emotions. Despite M’s health challenges and developmental delay, he

was scheduled to graduate high school that year. We were working with his mother and different organizations to plan a celebration for him with a mariachi band, personalized graduation cake, and photography to celebrate this important milestone. Unfortunately, M. was admitted to the hospital for several weeks and it became apparent to the medical team within the hospital and our staff that he was having a sustained decline and perhaps nearing the end of life.

During this time, our team was talking with mom about her hopes and dreams for her son. The one thing she made crystal clear was her desire to see M. graduate high school. In collaboration with the palliative care team and his psychosocial team at the hospital, we were able to contact and work with his high school to create a quick, but special, graduation ceremony. His mom wanted many people who had been in M's life present for the ceremony and we were able to invite the people mom had requested.

Collaboration was key as I worked with the Certified Child Life Specialists and Music Therapists working with him at the hospital to come up with some ideas and ways we could make the ceremony as authentic and individualized as possible. The child life team procured a graduation cake, ordered a cap and gown with school colors; we even had the hospital photographer involved to take pictures of the patient, family, and his guests. This all came together in a matter of days.

I vividly remember walking into the hospital that day. M's room was in a corner and the room was overflowing with his family, medical team members, some of whom had been caring for him since he was an infant, members of our hospice team, his home OT/PT providers, his daily home PDN, his teachers, and the high school principal. The room next door was cleared and served as a reception room for people to enjoy punch and cake, and place graduation cards and gifts. The love for M. and his family was palpable.

Once everyone had arrived, the Music Therapist played Pomp and Circumstance and the school staff surrounded his bedside to present M. with his diploma while we all cheered and celebrated this milestone. At mom's request I used her cell phone to capture the moments so she had them immediately; I also took photos of the numerous groups of people who were important to M. and his family while M. was in his cap and gown. His primary doctor even celebrated by singing a round of M's favorite song with him. It was a joyous celebration, but it was also bittersweet for the medical staff as many of us knew this may likely be the last time we would see M. and hear his special laugh.

A few days later M. passed away, surrounded by his family, at the hospital. I was able to continue collaborating with the child life team in the hospital and personally delivered the keepsakes they had made to mom a week after his funeral. Mom expressed her gratitude for our services and spoke about cherishing the ability to see her son graduate.

Fast forward to 2020, living in times of COVID-19. K., an 18-year-old female with a hospice diagnosis of Cystic Fibrosis, came on to service as a senior in high school who was looking forward to walking across the stage and graduating with her friends. K. was looking forward to prom, senior week, and taking special trips with her friends. She had been out and about but being cautious as COVID-19 started to emerge. Nevertheless, she wanted to live her life to the fullest.

Her family had planned a surprise trip to the Houston Rodeo for K. to see Lizzo with her friends, complete with limo ride and front-and-center seats. Then COVID-19 came as did a “stay safe and stay at home order” which halted those hopes and dreams. The rodeo was cancelled, and the future was uncertain.

Previously, her Nurse Case Manager had connected her with a nonprofit that would allow her to obtain the prom dress of her dreams, free of charge. However, COVID-19 also prevented that organization from functioning. Even if prom wasn’t going to happen, I wanted to see if she and her family would like the opportunity to have a prom dress and be able to take photos and celebrate in their own way. K. was interested in this idea and was still hoping to be able to celebrate these milestones at a later date and work on her living legacy.

Then, I thought about M. and his graduation and realized that collaboration was the answer to finding new ways to celebrate these important milestones. I began collaborating with her hospital-based Certified Child Life Specialist, who had followed her for the past several years, as I knew their hospital typically did a prom and had some dresses that were clean and in storage. Together we worked on plans to Zoom together and offer dress options for her; she wanted something “outside the box” because she had “always done everything in her life inside the box.” We were able to collaborate and get K. the prom dress and she is looking forward to a potential summer prom date as her school worked hard to postpone the dance. Even in these uncertain times there are ways we can work towards honoring the living legacy perspective.

For teens, autonomy and intangible memory making and living legacy building can be the most poignant psychosocial interventions. Legacy making doesn’t always have to be about the heartbeat recordings, ink prints, plaster molds, or photos we create in those final moments of life. In fact, some of the most powerful moments I have experienced with patients and families are when we engage in active listening and allow storytelling and honoring those living legacies the patient and family have created. Maybe it’s a patient’s desire to finish a special LEGO set or accomplish their dream of riding in a special car. Perhaps it’s even smaller; maybe a mother voices her goal and dream of taking her daughter to a picnic in a park and have those “normal” moments we often take for granted. In the end, a question we should always ask the families and patients we serve is, “What are your hopes, dreams, or goals for you (patient) or your child?” We should strive to listen and honor those requests in creative new ways.

References:

Allen, R. S., Hilgeman, M. M., Ege, M. A., Shuster, J. L., & Burgio, L. D. (2008). Legacy activities as interventions approaching the end of life. *Journal of Palliative Medicine*, 11(7), 1029-1038.

Boles, J. (2018, Winter). L is for Legacy (Living). *ACLP Bulletin*, vol. 36 no. 1, pp. 6-10.
<https://www.childlife.org/docs/default-source/publications/bulletin/aclp-bulletin-winter-2018.pdf?i=463803>

Boles, J. C. (2014). Creating a legacy for and with hospitalized children. *Pediatric Nursing*, 40(1), 43-44.

Staudt, C. (2013). Whole-person, whole-community care at the end of life. *Virtual Mentor*; 13(12):1069-1080. doi: 10.1001/virtualmentor.2013.15.12.msoc1-1312.

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ADVANCE CARE PLANNING WITH A TEENAGER: EMPOWERING THEIR VOICE AND CHOICE AT END OF LIFE

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In pediatric palliative care, we know the benefits of starting early with families along a patient's illness journey - with providers getting to know the family, and the family getting to know us.

The following paper is a reflection on the therapeutic relationships developed between a pediatric palliative care team, hospice, and a mother and her daughter, and explores how early conversations about the end of life (EOL) can lead to profoundly meaningful changes in quality of life. Individual perspectives from three different providers are shared (Social Work, Psychology, and Nurse Practitioner) along with references to literature and reflections on the legacy of this special patient on our own learning in palliative care.

The three writers for this article had the incredible fortune to work with a young teenage girl, named Ruby, and her family during her life with cancer and eventual death. We share her story and the lessons she taught us here with permission from her mother, Cathie.



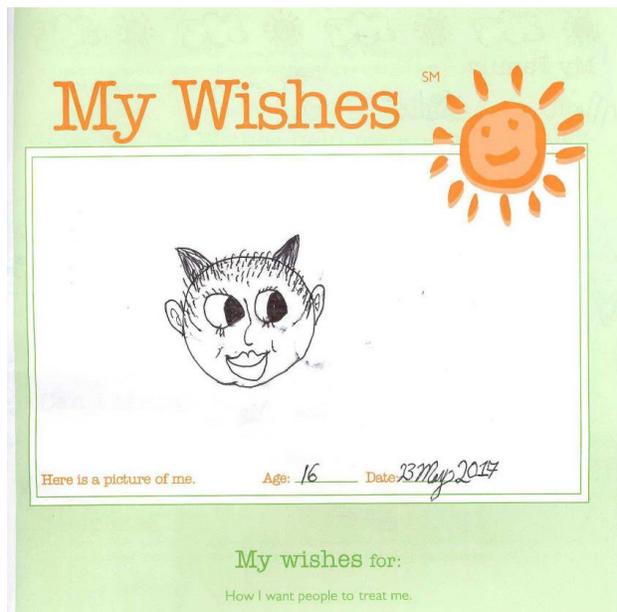
Ruby at her 8th grade graduation.
(Photo courtesy of her mother, Cathie)

Introduction to Palliative Care – Cristina Benki, PhD and Maggie Root, RN, CPNP-AC

The day we first met Ruby, she walked into the room wearing a soft beanie-type hat, wrapped in a fleece blanket for comfort. She had come from a dermatology appointment and was blunt in wanting her mother to answer questions first. "Mom, you talk to her first," she said as she fidgeted with her hat. But she eventually warmed to the meeting and spoke very clearly with us about her preferences on a diverse set of topics. We learned that she was an excellent student

who loved History and enjoyed learning; for example, when we asked her what three wishes she would make with a magic lamp, she said her first wish would be to travel back in time to Ancient Greece or the Middle Ages. She was beloved by her teachers because she was engaging and not afraid to ask hard questions or point out her teacher's mistakes. She loved to read and was a big fan of the *Harry Potter* series. She liked to think of herself as belonging to the House of Slytherin, as their members were cunning and witty. Ruby loved the music of Lana del Rey, but also liked classic rock bands like Foreigner and Journey (like her mother). She had an affinity for soft, plushy textures, and loved to cuddle her dog, Carly (who was also very soft). While she was in treatment with us, she adopted a cat named Harold with whom she bonded closely. She did not like aromatherapy or smells in general. And she liked to doodle, but not color. She was fiercely supported by her mother, who joined our visits and listened intently to what Ruby wanted. In fact, Ruby was clear that she did not like to be touched *unless* it was by her mother. There are many memories of Ruby that stick out in our minds, but one of the most striking features that Ruby possessed was her honesty. She had a quickness and maturity about her that led her to speak frankly with adults – and she was not afraid to speak about death.

Our team was introduced to Ruby about six to seventh months after she had been diagnosed with a rare glioblastoma in her brain stem, which was thought to have a prognosis of a few months to a year. When we met her, she had already undergone several months of radiation therapy and a trial of tumor-directed medication therapy. She was suffering fatigue and nausea, as well as less common side effects of the treatments, including acne all over her face and body, and hair loss. The acne was particularly painful as she described that “everything hurts.” She said she was feeling increasingly depressed, and she was angry about what was happening to her body. With this context, Ruby and her mother decided not to pursue additional tumor directed therapy because the end was coming quickly, and death was inevitable.



Cover of Ruby's "My Wishes" ACP

Like all teenagers, Ruby's health spanned both biomedical and psychosocial needs. Before her cancer diagnosis, she struggled with depression starting in puberty. She had just started psychotherapy a few months prior to diagnosis. At the time of her diagnosis, she was also started on a trial of antidepressants because her depression had been worsening. While Ruby's situation was unique, research indicates that depressive symptoms are common in children and adolescents diagnosed with cancer (Barker, Beresford, Bland, & Fraser, 2019). Depressive symptoms have been associated with changes in appearance and the presence of distressing symptoms, both of which Ruby experienced (Cataudella & Zelcer, 2012; Levine et al, 2017).

The unique combination of Ruby's history of depression and her cancer diagnosis seemed to lead Ruby toward very real and candid reflections on her own mortality. She wanted to talk about her fears and wishes and she wanted to be able to have very direct conversations about the dying process. During our first meeting, Ruby told us that she didn't want us to "sugar-coat" her illness or try to find a silver-lining. She wanted permission to talk about these things that we adults often consider taboo, and she wanted to talk about them with her health care providers.



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In psychotherapy, the therapeutic relationship is key to supporting patient change in treatment. In fact, Norcross and Wampold (2011) have highlighted in their outcomes research that the therapeutic relationship accounts for why clients improve (or fail to improve) at least as much as the particular treatment method (e.g. Cognitive-Behavioral Therapy). Knowing that our therapeutic relationship is so influential, psychologists work very hard to consider their power in the therapy relationship, meaning power as a doctor or "expert" when working with a child. Psychologists and therapists think about the information they share (or don't share), and how this impacts the decisions that are made in treatment. As social psychologists have long been studying, people make decisions about how to act or behave in uncertain or confusing situations based on the information they receive from those around them, especially experts (see Milgrim, 1974; Turner, 1991). And so in health care, we have and must continue to work toward care models of shared decision making, models that account for how "expert" power

influences decision-making, particularly at end of life (e.g. Coughlin, 2018; Gabel, 2012; Kon & Morrison, 2015; Wyatt et al, 2015). Sometimes this means that we need to use our power to give patients and families “permission” to talk about dying and all of the feelings that come with that exploration.

From a palliative care perspective, the inclusion of adolescents in advance care planning has been shown to improve patients’ understanding of decisions surrounding end of life (Lyon, Jacobs, Briggs, Cheng, & Wang, 2013). It is also important to note that engaging seriously ill adolescents in advance care planning (ACP) discussions has not been shown to increase anxiety or depressive symptoms (Lyon, Jacobs, Briggs, Cheng, & Wang, 2014). Furthermore, bereaved parents of children with serious illness who engage in ACP have been shown to have less regret around decisions made at the end of their child’s life (DeCoursey, Silverman, & Wolfe, 2019).

In our first clinic visit with Ruby, we openly discussed the dying process from a physical and psychoemotional perspective. Ruby was clear in telling us that she wanted additional information, and her mother supported her information-seeking around possible end of life scenarios. With this context, we asked her in that first meeting if she would like to take a look at some ACP workbooks like *My Wishes* (Aging with Dignity, 2020) and *Voicing My Choices* (Wiener et al., 2012). Research has indicated that adolescents and young adults with life-limiting illness desire an opportunity to record treatment preferences and how they want to be remembered after death (Wiener et al., 2008). Furthermore, they prefer an ACP guide that is tailored to their developmental needs (Wiener, Zadeh, Wexler, & Pao, 2013). Without ACP, family members of adolescents with cancer are often unaware of the patient’s preferences for EOL interventions (Friebert et al., 2020; Jacobs et al., 2015). The workbooks described above provide a self-paced option for patient and caregivers to explore with guidance from health care providers.

Ruby told us that she was willing to take the ACP guides home but was not certain that she would fill them out. So with reassurance that we had no expectations, we introduced the forms to her so that she could continue exploring with her mother at her own pace – she liked the idea of having control of the process. When she returned during our next visit, she voluntarily, and without reservation, reported that she had completed the entire *My Wishes* packet in one sitting. She had written her first draft in pencil and requested clarification on whether she could change her mind from what she had written. After clarifying that indeed, Ruby was free to change her values and stated desires at any time, and for any number of times, she asked for another copy so it could be completed in pen. Having permission to change her mind and support in exploring the array of options in her care was empowering. It remained important to validate the sense of control that Ruby had over her treatment decisions, especially when she was unable to control many other aspects of her disease.

Over the course of our time with her, we engaged in a series of ACP discussions. Ruby completed two more ACP documents, with her most detailed form, *Voicing My Choices*, done in collaboration with her hospice team. These forms then helped to propel discussions forward about Ruby’s values and her quality of life - to help us as providers focus on what was most

important to her, what she enjoyed, and how she could live her life the way she wanted. We talked about the foods she craved (hot dogs), the trips she would take with her mother to the beach, and her mixed feelings on whether or not she wanted to attend school in the fall.

Wish #1

My Wish for how I want people to treat me
(Check any box that you would want.)

I wish to be cared for with kindness and cheerfulness.

I wish to have my hand held and to be talked to whenever possible. *mom*

I wish people would pray for me.

I wish to have my favorite things with me if possible. My favorite things are:
my soft gray blanket, petsy Johnson blanket, my pillow
my good night moon bunny bear wearing a dress, fuzzy socks

I wish to have pictures of my favorite people and things.

If I am very sick and may die, I wish to be:

In the hospital.

At home.

Somewhere else: _____

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One of the biggest decisions we remember is when Ruby and her mother agreed to move to a new home. As they had been exploring her wishes, Ruby talked about moving from their family property to a new home in an adjacent city. She wanted to move and her mother listened, acting swiftly to make it happen. Within a month or two, they sold their house, moved spaces, and settled into a new home. It was after this move that we saw the most drastic change in Ruby's mood and appearance. She returned to clinic happy, silly, laughing and joking, and more carefree than we had ever seen her. This was also around the time that she learned that her tumor appeared smaller on recent scans. Both the move and the news about her tumor seemed to renew both her and her mother's perspective on how to focus her energy, and she

made the decision to return to school. She was sleeping well, eating well, and feeling good. And because of these significant improvements in her quality of life, Ruby did not want to come to more doctor appointments if it wasn't necessary, so we all agreed to transition away from office visits with our palliative care team (that required significant transit time), while her hospice team continued to provide support to her at home.

Wish #2

My Wish for how comfortable I want to be

I do not want to be in pain.

I want my doctor to give me enough medicine to stop my pain, even if it makes me sleepy.

If I don't feel good, I want my caregivers to do whatever they can to help me feel better.

These things make me feel good:
sleeping

I like to be read to. These are the books I like:

I like to play games. These are my favorite games:

I like to listen to music. These are the types of music I like:
Lana del Rey

These are some things that I do not like:
people being loud

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Addition of Hospice – Jennifer Adams, LCSW

As a social worker who has worked with children with serious illness for over a decade now, I have experienced many different approaches to how parents and providers talk to children and

adolescents about their illness. Many parents believe that talking with their children about dying and serious illness will cause more distress. Sometimes this is true, and it is important to me as a social worker to honor the wishes of a child and their families, especially when it comes to the impossibly difficult conversation about the child's end of life. But in my experience, many children, especially adolescents, want to discuss this "taboo subject." In fact, an article by Friebert et al reveals that 100% of patients surveyed stated they wanted honest information from their providers and 86% wanted to have ACP conversations when they are first diagnosed opposed to when they were nearing end of life (Friebert et al, 2020).

In this same study, only 39% of parents and caregivers accurately reported that their children preferred to have conversations early in treatment related to their goals of care. Furthermore, parents and the adolescents in the study were incongruent in the patient's preference for "dying a natural death" or being on life support, specifically 60% of adolescents stated that they did not prefer aggressive EOL measures if they were dying. In fact, most preferred to die at home. In contrast, parents/caregivers believed that their child wanted to be in a clinical setting like a hospital during the dying process (Friebert et al, 2020).

Reading this article was not surprising to me given my years of working as a pediatric palliative care social worker. My time with Ruby comes to mind. I met her in my first year of working in palliative care. She came to service after being treated for a brain tumor at a local hospital. She continued intermittent palliative chemotherapy in an outpatient setting to alleviate some of her symptoms but was very clear about what she wanted and what she did not want when it came to her treatment and goals of care. She had completed *My Wishes* with the hospital staff and shared this with me early into our relationship. Typically, I had these conversations with families when patients were either already at EOL and unable to advocate for themselves, or when talking privately with patients because they worried about upsetting their parents. Friebert et al (2020) state:

Among children with complex chronic conditions, pediatric advance care planning (pACP) decreased suffering at the EOL and improved families' quality of life. Lack of ACP has been associated with poor communication, increased hospitalization, poor EOL quality of life, poorer adherence to patient's EOL preferences, and legal actions.

For Ruby and her mother, having completed her own ACP guide allowed for them to focus on the present and not on the "what ifs" of treatment options and her inevitable decline. And I believe these early conversations about her wishes at EOL and treatment preferences allowed for her to have a better quality of life both while on hospice and while she was dying.

The day I met her I realized she was no nonsense and that the often delicate dance I do with most patients and families of discussing "difficult" topics would not work with her. She wanted honest, frank conversations related to her care and the possible symptoms she might experience as she declined. She had strong opinions and was not afraid to share these with our team and her mother. At the same time, she was a typical teen who loved angsty music, Harry Potter, and her pets. She would always greet me with a hug when I arrived at her home for my

weekly visits and spend time talking with me, really teaching me, about the differences between Harry Potter and Lord of the Rings, why the music of Lana del Rey is sooo good, and how energy work isn't going to cut it for her. I had long conversations with her mother when she would tell me "she was too tired to talk" and retreat to her room. It became our little joke that she had enough of me and needed to hang out with her kitty away from all the talking and processing. Losing her daughter was going to be tough, Cathie would mention, and despite this Ruby's mother did not push her daughter to seek further cancer-directed treatment. She had suffered enough with past treatments and wanted to spend the rest of her time being happy. And for a teen who had struggled with depression in the past, she was happy during the time she was on hospice and at peace with dying.

The Final Months

About 3-4 months after we first met Ruby, waves of life changes occurred. The wildfires in Northern California significantly impacted her family and local community. Her health also started to decline again, as her cancer progressed. Ruby decided to spend more time connecting with all of her family members. She also adopted a new puppy, who served as a happy distraction from the challenges her family faced. She was often surrounded by animals when her hospice staff visited as she usually had Harold, her kitty, in her lap. She and her mother found new places in San Francisco to explore and enjoyed sharing stories of the new foods and pets they encountered. And through this time, Ruby maintained her witty demeanor, often teasing her hospice nurse and social worker as they continued to visit weekly with her, her mom, and their zoo of animals.



**Ruby with her cat, Harold
(photo courtesy of her mother, Cathie)**

The focus on home time allowed extra connection between mother and daughter. Ruby's mother shared that in their intimate bedtime conversations, Ruby would talk about her fears and hopes for her life and death. She and her mother would cuddle together, holding hands, and talk until late into the night.

After being cared for at home for much of her disease, Ruby was admitted to the hospital for symptom management and EOL care. Because Ruby's wishes had been so clearly articulated and discussed with her mother, Cathie still had a guide when Ruby's communication ability declined. As she had from the start of treatment, Cathie continued to amplify Ruby's voice, serving as an advocate and caregiver. Remarkably, Ruby spent very little time in the hospital and most of it in the care of hospice. As a result, unlike some other patients, she did not have relationships with hospital staff, such as nurses or child life specialists. So in addition to early

conversations with palliative and hospice providers, her completed ACP documents provided clear instructions in her own voice about what she preferred and wanted at a time when she could not talk. Hospital staff were grateful that her family had knowledge of Ruby's preferences for her care. Providers who were new to Ruby were able to learn about her personality, style and desires for how she wanted to be cared for during those final moments. And importantly, it allowed her mother, father and sister to be present fully with Ruby without having to make more decisions.

Wish #4
What I want my doctors and nurses to know

I am a very special person, and these are some of the things that I would like everyone that takes care of me to know.

I want you to call me by my name or nickname: Ruby

I want you to tell me your name, why you are here, and what you are going to do to me before you do it.

If I need a painful procedure, I would like you to use numbing cream whenever possible.

I want to be told when something may hurt me.

Whatever I tell you about me, I want you to keep private, but you can tell these people:
 (I understand that others may need to know if it affects my care.)
mom

I understand that sometimes you will need to touch my body or examine me, but please respect my privacy and dignity by:

Closing the curtain.

Covering me with a gown or sheet.

Closing the door whenever possible.

I don't mind having these people in the room when I am being examined:

If I feel angry, happy, sad, silly, scared or lonely, I would like to be able to talk to you about it.
 These things make me feel safe:
my mom

I want all of my questions to be answered honestly and in words that I can understand.

I know I need time to rest and sleep, but I also want to have time to play.

These are the other things I would like you to know about me:

11

Page 11 of Ruby's "My Wishes" ACP

Sometimes people can feel very uncomfortable when they are ill.

For example, they might have pain, become sleepy or not feel like themselves. It is important for others to know how you want to be treated and what will make you feel more comfortable, especially if you become very ill and cannot express your wishes on your own.

How I Want To Be Comforted

My Voice

My favorite music/food is:

Lana Del Rey / mac-n-cheese

The kinds of books, stories, or readings I like, are:

Harry Potter / History

Other thoughts I have about treating my pain, or helping to make me comfortable, are:

make me corn fry
nothing on my face, NO breathing tube

I would also like:

~~no~~ Harold on my lap.

My Choice These are a Few of the Comforts Important to Me

If I look like I am uncomfortable in the following ways: (Please check all that apply)

I want treatment to help me, if I:

- Look sad
- Am irritable/frustrated
- Look nauseated
- Look confused
- Look like I am having a hard time breathing
- Am cold or hot

If I am in pain, I would like:

- My doctor to give me enough medicine to relieve my pain, even if that means I will not be awake enough to interact with my friends or family.

Or,

- To receive medications to reduce my pain but I do not want to be too sleepy

Other things that are important to me are:

- If I am not able to get to the bathroom in time, please change my clothes and sheets right away so that I am always clean.
- If friends are coming to visit, please dress me, comb my hair and do whatever else is needed to help make me look like myself.
- Massages whenever possible as long as they do not cause me discomfort.
- To be bathed.
- To have music playing in my room.
- To have my favorite foods available.
- To be read to.

SCANNED



Page 4 of Ruby's "Voicing My Choices" ACP

Reflections and Perspectives

From Cristina Benki. Through the course of writing this paper, I reached out to Ruby's mother, Cathie, and had the honor of remembering her daughter's legacy together, more than two years after Ruby died. In hearing from Cathie how she remembers how Ruby lived at the end of her life, she described her daughter as happy, maybe for the first time since puberty. I strongly

believe that Ruby and her mother created this happiness together. Her mother gave her permission to explore not just the world around her, but the emotional world inside of herself – what made her excited, what make her scared or sad, and what brought her joy. It was through the intimacy and strength of their relationship, and her mother’s ability to share decision-making with her, that Ruby had the power to live how she wanted and where she wanted during that last year. Without these conversations she may have continued to suffer, persisting through treatments that she did not want in order to appease others who thought it was best for her.

For me, Ruby’s story is one that really leans into the fears that we as providers can have about talking about death and dying with young patients. It challenges us to consider our own assumptions and biases when exploring life and death with children. When we say, “She’s not ready to talk about that,” or “He’s not thinking about those things yet” with respect to ACP, then we really need to consider from where those interpretations are coming. Is it really reflecting the process of our patient and family, or is it more about me (the provider) and my feelings about the topic? Because if we are operating from our own fears, we are not sharing power with our patients, nor are we empowering them or giving them agency to make their own choices. I learned from Ruby that talking about death is not synonymous with giving up hope. I learned that sometimes in an effort to comfort our patients, we “sugar-coat” information, which at its best can feel like withholding, and at its worst can feel like lying. I learned that talking about dying can mean that we can talk more fully about how we want to live. And I learned that teenagers and children have deep wisdom to share with us when we are willing to hear it. I am grateful to Ruby for sharing her wisdom and bravery with me, and thankful that I was able to listen.

From Maggie Root. Ruby was the perfect patient for a palliative care provider to meet – one of those people you don’t soon forget. She was remarkably observant of the interactions and words of other people and expected the truth from the adults around her. She (thankfully) seemed to forgive me when I stumbled over how to respond or used ‘softened’ language in what would normally be delicate conversations. Ruby didn’t come to our clinic to dance around death – there was no masquerading. She asked pointed questions that revealed a teenager who had considered her own mortality and was making sense of an ever-evolving life. This led to re-goaling over time (Hill et al., 2014; Mack et al., 2016), as Ruby’s relationships with people, pets and the world around her changed. As Ruby’s disease, treatment goals and values evolved, so did her experience of symptoms. The words of oncology nurse expert Margo McCaffery resonate with me when I reflect on this case. McCaffery (1968) writes that pain is what a patient says it is, occurring when and where a patient says it occurs. Ruby was able to articulate unique ways in which her cancer and associated treatments impacted her quality of life, in body, mind and soul. Some of these were effects that I would not have considered given her treatment course. It was because of her steadfast self-advocacy that her care team was able to appreciate the harm that therapies had on her physical and mental health. Ruby reminded me that it was up to us as health care providers to listen in and truly *hear* the meaning in our patient’s words. She may not have liked loud voices, but her quiet words were booming in other ways.

From Jennifer Adams. Working with Ruby was such a privilege and she taught me so much. I learned that being a social worker with children and teens with chronic illness meant to really listen to what they want for themselves when it comes to treatment and goals of care. In addition, Ruby taught me that saying “no” to treatment should be an option when adolescents and children have a terminal, untreatable illness even if that means they will likely die sooner than when we “hope.” Sometimes what we perceive to be as minor symptoms can be distressing to those who are actually experiencing them and that we as providers need to acknowledge how hard they may be for the individual. I learned to always take advantage of a nice, soft blanket and that puppies and kittens in our laps can make difficult conversations seem a bit easier. It was an honor to witness the unconditional love of a mother who turned Cheez-Its into paste for her daughter as she was dying and encouraged her daughter to make her own informed health care and EOL decisions.

As a social worker who continues to work with youth and children with chronic illness, I advocate more for their voices to be heard even if that creates some uncomfortable moments with my team members and with parents. I have better equipped myself as a social worker for difficult conversations about treatment options and EOL with teenagers because of Ruby’s bravery to speak up. I thank my strongly opinioned, fan of all things soft and cozy, Harry Potter reader, lover of “being in nature but not for nature being on me” for giving me the courage to be this type of social worker. I will close with a Harry Potter quote I shared at her celebration of life, ironically in nature, surrounded by huge redwoods connecting us all with something larger than ourselves: “But know this, the ones that love us never really leave us. And you can always find them in here (points to heart).” I pictured her in this moment rolling her eyes at my sentiment and then giving me a giant hug, regardless.

Conclusion

Our goal in sharing our time with Ruby and the lessons she taught is to support our fellow providers in considering how we approach the often intimate and complex work of EOL discussions with children, teens and young adults. Because our focus has been on encouraging providers to listen to and amplify the voices of our patients, we would like to end with Ruby’s words from her *Voicing My Choices* ACP document, guiding us on how she wanted to be remembered.

What I Would Like **My Family and Friends** to Know About Me

My Choice It is important to me that my family/friends:

- Get along
- Take care of themselves
- Take care of one another
- Respect my wishes, decisions and choices even if they don't agree with them
- Get counseling or find a support group for themselves and/or my siblings if they are having a hard time

My Voice

I want my family to know that I am thankful for their love and support. I am especially thankful for:

my whole family.

I want my friends to know that I am thankful for their love and support. I am especially thankful for:

Elena, Emily, Emely, Faith,

If I have hurt or upset any of my friends, family or others, I wish to be forgiven for:

When I have been hurt or upset by my family, friends, or others, they should know I forgive them for:

being mean.

These are the things that are important to know about me:

The things that give me strength are:

Kitty

The things that give me joy are:

Kitty, music, momma, Rocco, Nicky

Remembered

If it is more comfortable, you choose to let others decide about a funeral, a memorial service, and caring for your body after death. Or you can use these pages to voice your preferences.

My Remembrance

- I prefer not to be a part of planning my service.
- I prefer to plan my service. (Please check all that apply)

The type of service(s)

I would like are:

- Funeral
- Memorial service
- Celebration of my life

cake & pie

I would like:

- To be **buried**
- To be **cremated**
- An **open casket**
- A **closed casket**
- To **donate my body** to science
- To be an **organ donor**
- A **limited autopsy**
- A **standard autopsy**
- A **research protocol autopsy**
- I would like my healthcare agent to make the autopsy decision

The clothes that I would like to be wearing (for service/cremation/burial) are:

black dress, Wednesday Adams dress!

The items that I would like to be with me are:

The music/food I want at my service are:

all my favorites *Hot dogs, hamburgers*
mac-n-cheese, pie, cake, ice cream
pizza, Caesar salad,

The people I would like to be present are:

family, friends, Mr. Strehle, Jennifer Adams, Doctors
Ms. Piper, Richard Gnome, and immediate family's friends. *and immediate family*

I would like these readings at my service:

Death is but a walking shadow (Shakespeare)

I would like these other arrangements at my service:

flowers/Roses/whit lilies

If my family or friends want to make contributions or donations I would like them to go to:

UCSF pediatric cancer research. (Glioblastoma multiforme) brain stem

Note: Consent to publish patient information and photographs was obtained from the patient's mother. University of California San Francisco and Vanderbilt University confirmed this paper as exempt from requiring IRB approval.

References

- Aging with Dignity. (2020) *My Wishes*. <https://fivewishes.org/shop/order/product/pediatric-my-wishes>. Accessed July 24, 2020.
- Barker, M. M., Beresford, B., Bland, M., & Fraser, L. K. (2019). Prevalence and Incidence of Anxiety and Depression Among Children, Adolescents, and Young Adults With Life-Limiting Conditions: A Systematic Review and Meta-analysis. *JAMA Pediatrics*, 173(9), 835–844. Advance online publication. <https://doi.org/10.1001/jamapediatrics.2019.1712>
- Cataudella, D. A., & Zelcer, S. (2012). Psychological experiences of children with brain tumors at end of life: parental perspectives. *Journal of Palliative Medicine*, 15(11), 1191–1197. <https://doi.org/10.1089/jpm.2011.0479>
- Coughlin K. W. (2018). Medical decision-making in paediatrics: Infancy to adolescence. *Paediatrics & Child Health*, 23(2), 138–146. <https://doi.org/10.1093/pch/pxx127>
- DeCoursey, D. D., Silverman, M., Oladunjoye, A., & Wolfe, J. (2019). Advance Care Planning and Parent-Reported End-of-Life Outcomes in Children, Adolescents, and Young Adults With Complex Chronic Conditions. *Critical Care Medicine*, 47(1), 101–108. <https://doi.org/10.1097/CCM.0000000000003472>
- Friebert, S., Grosseohme, D. H., Baker, J. N., Needle, J., Thompkins, J. D., Cheng, Y. I., Wang, J., & Lyon, M. E. (2020). Congruence gaps between adolescents with cancer and their families regarding values, goals, and beliefs about end-of-life care. *JAMA Network Open*, 3(5), e205424. <https://doi.org/10.1001/jamanetworkopen.2020.5424>
- Gabel, S. (2012). Power, leadership and transformation: The doctor's potential for influence. *Medical Education*, 46, 1152-1160. <https://doi.org/10.1111/medu.12036>
- Hill, D. L., Miller, V., Walter, J. K., Carroll, K. W., Morrison, W. E., Munson, D. A., Kang, T. I., Hinds, P. S., & Feudtner, C. (2014). Regoaling: A conceptual model of how parents of children with serious illness change medical care goals. *BMC Palliative Care*, 13(9). <https://doi.org/10.1186/1472-684X-13-9>
- Jacobs, S., Perez, J., Cheng, Y. I., Sill, A., Wang, J., Lyon, M.E. (2015). Adolescent end of life preferences and congruence with their parents' preferences: Results of a survey of adolescents with cancer. *Pediatric Blood Cancer*, 62(4), 710-714. <https://doi.org/10.1002/pbc.25358>
- Kon, A. A., & Morrison, W. (2018). Shared-decision-making in pediatric practice: A broad view. *Pediatrics*, 142(Supplement 3), S129-132. <https://doi.org/10.1542/peds.2018-0516B>

- Levine, D. R., Mandrell, B. N., Sykes, A., Pritchard, M., Gibson, D., Symons, H. J., Wendler, D., & Baker, J. N. (2017). Patients' and Parents' Needs, Attitudes, and Perceptions About Early Palliative Care Integration in Pediatric Oncology. *JAMA Oncology*, 3(9), 1214–1220. <https://doi.org/10.1001/jamaoncol.2017.0368>
- Lyon, M. E., Jacobs, S., Briggs, L., Cheng, Y. I., & Wang, J. (2013). Family-centered advance care planning for teens with cancer. *JAMA Pediatrics*, 167(5), 460–467. <https://doi.org/10.1001/jamapediatrics.2013.943>
- Lyon, M. E., Jacobs, S., Briggs, L., Cheng, Y. I., & Wang, J. (2014). A longitudinal, randomized, controlled trial of advance care planning for teens with cancer: anxiety, depression, quality of life, advance directives, spirituality. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, 54(6), 710–717. <https://doi.org/10.1016/j.jadohealth.2013.10.206>
- Mack, J. W., Cannavale, K., Sattayapiwat, O., Cheung, B., Chen, L. H., Cooper, R. M., & Chao, C. R. (2016). Care in the Final Month of Life among Adolescent and Young Adult Cancer Patients in Kaiser Permanente Southern California. *Journal of Palliative Medicine*, 19(11), 1136–1141. <https://doi.org/10.1089/jpm.2015.0527>
- McCaffery, M. (1968). *Nursing Practice Theories Related to Cognition, Bodily Pain, and Man-Environment Interactions*. University of California Print. Office.
- Milgrim, S. (1974). *Obedience to Authority: An experimental view*. New York: Harpers & Row.
- Norcross, J. C., & Wampold, B. E. (2011). Evidence-based therapy relationships: Research conclusions and clinical practices. *Psychotherapy*, 48(1), 98–102. <https://doi.org/10.1037/a0022161>
- Turner, J. C. (1991). *Social Influence*. Pacific Grove, CA: Brooks/Cole.
- Wiener, L., Ballard, E., Brennan, T., Battles, H., Martinez, P., & Pao, M. (2008). How I wish to be remembered: The use of an advance care planning document in adolescent and young adult populations. *Journal of Palliative Medicine*, 11(10), 1309–1313. <https://doi.org/10.1089/jpm.2008.0126>
- Wiener, L., Zadeh, S., Battles, H., Baird, K., Ballard, E., Osherow, J., & Pao, M. (2012). Allowing adolescents and young adults to plan their end-of-life care. *Pediatrics*, 130(5), 897–905. <https://doi.org/10.1542/peds.2012-0663>
- Wiener, L., Zadeh, S., Wexler, L. H., & Pao, M. (2013). When silence is not golden: Engaging adolescents and young adults in discussions around end-of-life care choices. *Pediatric Blood & Cancer*, 60(5), 715–718. <https://doi.org/10.1002/pbc.24490>

Wyatt, K. D., List, B., Brinkman, W. B., Prutsky Lopez, G., Asi, N., Erwin, P., Wang, Z., Domecq Garces, J. P., Montori, V. M., & LeBlanc, A. (2015). Shared Decision Making in Pediatrics: A Systematic Review and Meta-analysis. *Academic Pediatrics*, 15(6), 573–583.
<https://doi.org/10.1016/j.acap.2015.03.011>

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ADDRESSING DISPARITIES IN PEDIATRIC PALLIATIVE CARE IN THE CONTEXT OF DEATH AND DYING

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As a racial justice movement sweeps a country gripped by the COVID-19 pandemic, the collective rage, despair, and increased public awareness of this moment require that medical systems look within to interrogate and diagnose their complicity in perpetuating inequities. As many have noted, it is no coincidence that COVID-19 disproportionately infects and kills people of color. In April, *New York Times* columnist Charles M. Blow observed that, “in practice, in the real world, this virus behaves...like a heat-seeking missile toward the most vulnerable in society.”¹ Anthropologist Charles Briggs has explained that racialization of disease is an old trend, as “underlying structural factors and policy decisions predictably enable the virus to strike racialized minorities the hardest.”²

The study of pediatric palliative care disparities is a particularly unique and potentially probative lens through which to better understand the dynamic ways that biology and social systems intersect and build upon one another to create the underlying inequities revealed and exacerbated in the current pandemic crisis. As pediatricians, we know that our engagement with patients occurs during a critical time of development, and that an individual's foundation of health is established in childhood. These have longstanding impacts that follow into adulthood, impacting health, quality of life, and the ways that people can expect to live and die. The needs of the pediatric patient and family intensify with serious life-limiting illness. Familial and generational experiences with the medical system (many negative) necessarily impact the experience of the child, family, and providers involved.

Ample data shows that poor and ethnic minority children experience disparities in the medical care that they receive,^{3 4 5} which are reflected ultimately in outcome disparities in a myriad of conditions that may follow them into adulthood. In light of this, one might equally assume that disparities exist in the pediatric palliative care context. But the ability to effectively study pediatric palliative care disparities is currently limited, due to a lack of meaningful data. The benchmarks of palliative care efficacy—such as site of death, intensity of medical care at end of life, and hospice engagement prior to death—are adult-focused, and do not tell an adequate story of the pediatric patient. To assess whether a disparity in care exists, one must “separate differences that arise from patient preferences or diverse clinical trajectories of various medical conditions from disparities attributable to discrimination or differential access to the health care system or exposure to the environment.”⁶ But palliative care benchmarks may be informed by patient preferences based on family values and cultural beliefs, just as readily as they may be a reflection of a systemic disparity, such as differential access to health

care. These benchmarks are not adequate, by themselves, to facilitate effective pediatric palliative care disparities research.

In order to understand the disparities that exist within pediatric palliative care, we must consider the social context in which the patient and family live, and their historical interactions with the medical system. For example, Johnston and colleagues have noted that disparities in site of death may reflect a culturally driven or family preference, limited engagement with palliative care and advance care planning, hospice availability, and structural factors which make caring for a dying child difficult at home; likely it is some combination of all of these factors.⁷ The limited data that exist suggest that there are differences in site of death according to ethnicity and socioeconomic status. In 2007, Feudtner and colleagues performed a study of death certificate information in all 50 states from 1989 to 2003 and found that while the overall percentage of children with complex chronic conditions dying at home increased, non-Hispanic black and Hispanic white children with complex chronic conditions were 40% to 50% less likely to die at home than white/non-Hispanic children.⁸

Similarly, Johnston and colleagues performed a retrospective analysis of children with complex chronic conditions using a California state administrative database, and found that living in a low-income neighborhood was associated with increased odds of hospital death and receipt of a medically intense intervention within 30 days of death, and that Hispanic and “other” race and/or ethnicity were associated with hospital death.⁹ A similar pattern was seen within the pediatric oncology population, whereby publicly insured and ethnic minority children were more likely to receive intense end-of-life care and to die within the hospital.⁷ In considering potential etiologies of this disparity, authors Bona and Wolfe noted that poverty may account for some of this relationship—both because pediatric palliative care is a limited resource that is available primarily at larger academic centers, and because regardless of pediatric palliative care consultation, “poor families may feel less able to support a child dying...at home.”¹⁰ One can imagine that decisions about site of death reflect a complex interplay of family cultural values and socioeconomic realities.

Provision of goal concordant care is a central tenet in pediatric palliative care; evaluation of this requires an understanding of family goals and values and how these were reflected in medical decisions. While the adult literature is replete with studies showing racial and ethnic differences in end-of-life decision-making, the pediatric data is scant in comparison. Keele and colleagues evaluated characteristics associated with discussion of limitation or withdrawal of life support using a large sample of children found through the Pediatric Critical Care Research Network and found that Black race was independently associated with a lower likelihood of discussing limitation or withdrawal of life support.¹¹ Similarly, Moseley and colleagues studied the medical charts of 38 infants who died in a NICU in the Midwest and found that among the 61% of charts in which a physician documented recommending withdrawal or withholding of life-sustaining medical treatment, parents of white infants were more likely to agree to those limitation compared with parents of black infants (80% vs 62% respectively).¹² This finding is not generalizable, but hypotheses to explain these racial and ethnic differences in the adult context are still relevant to the pediatric patient; they include poor provider-patient/family

communication, lack of racial concordance between provider and patient/family, patient/family income or educational attainment affecting understanding and/or access to health care, and mistrust of health care providers.¹² Patients and families bring the historical context of their own prior experiences with the medical system to these fraught conversations. Increasing provider sensitivity and understanding of this will improve communication overall.

It is incumbent upon individual medical care providers to hold themselves, their colleagues, and the medical systems for which they work to a higher standard of equity. For clinicians at the bedside, this starts with the personal work of recognizing our own biases. Often these may be implicit, or unconscious, but they have real impacts on patients' experience of care, and a variety of health outcomes. This is introspective, and often painful work, and individuals and health care systems must prioritize it. As palliative care providers, we must expand our understanding of how we assess patient and family goals and values, and consider discussion of prior experiences of discrimination and racism within the medical system to be a routine part of the consultation. The simple act of acknowledging the presence of bias goes a long way in establishing trust with patients, and may allow them to more easily align with our teams. Just as we understand that decisions about goals of care and site of death are informed by poverty and other systemic factors, we must acknowledge the ways that prior experiences of discrimination impact trust in the medical system overall, and the decisions that families make. Finally, it is important for us to create space within our teams for voices that are not often represented in medicine, as more diverse teams will be able to serve families with greater cultural competence.

As pediatric palliative care providers, we care for society's most vulnerable and thus are uniquely positioned to collect patient information critical to improving our understanding of disparities. We are in our infancy of understanding the complex ways that disparities in pediatric palliative care can reveal themselves, and further exploration is sorely needed. But recognition of the problem—the existence of inequities and the lack of adequate data collection to inform palliative pediatric disparities research—is a prerequisite to managing it.¹³ Our understanding of disparities in medicine will be improved with standardized collection of indicators of socioeconomic status, patient language, parental education, and patient self-described race and ethnicity, and incorporation of these indices into databases available to researchers. As clinical providers, we must become more facile at exploring the ways that patients and families live outside of the hospital, and the ways that the social contexts of their lives impact their health and ability to access medical care. The difficult work of recognizing and studying these disparities is an important step toward providing more compassionate and equitable care for the patients and families we serve.

References

1. Blow CM. Social Distancing is a Privilege. *The New York Times*. 4/6/2020, 2020; Opinion.
2. Briggs CL. From the cholera epidemics to COVID, racialization of disease is an old trend. University of California Press; 2020.

3. Sigurdson K, Mitchell B, Liu J, et al. Racial/Ethnic Disparities in Neonatal Intensive Care: A Systematic Review. *Pediatrics*. 2019;144(2).
4. Slain KN, Shein SL, Stormorken AG, Broberg MCG, Rotta AT. Outcomes of Children with Critical Bronchiolitis Living in Poor Communities. *Clin Pediatr (Phila)*. 2018;57(9):1027-1032.
5. Zhang X, Carabello M, Hill T, He K, Friese CR, Mahajan P. Racial and Ethnic Disparities in Emergency Department Care and Health Outcomes Among Children in the United States. *Front Pediatr*. 2019;7:525.
6. Linton JM, Feudtner C. What accounts for differences or disparities in pediatric palliative and end-of-life care? A systematic review focusing on possible multilevel mechanisms. *Pediatrics*. 2008;122(3):574-582.
7. Johnston EE, Alvarez E, Saynina O, Sanders L, Bhatia S, Chamberlain LJ. Disparities in the Intensity of End-of-Life Care for Children with Cancer. *Pediatrics*. 2017;140(4).
8. Feudtner C, Feinstein JA, Satchell M, Zhao H, Kang TI. Shifting place of death among children with complex chronic conditions in the United States, 1989-2003. *JAMA*. 2007;297(24):2725-2732.
9. Johnston EE, Bogetz J, Saynina O, Chamberlain LJ, Bhatia S, Sanders L. Disparities in Inpatient Intensity of End-of-Life Care for Complex Chronic Conditions. *Pediatrics*. 2019;143(5).
10. Bona K, Wolfe J. Disparities in Pediatric Palliative Care: An Opportunity to Strive for Equity. *Pediatrics*. 2017;140(4).
11. Keele L, Meert KL, Berg RA, et al. Limiting and Withdrawing Life Support in the PICU: For Whom Are These Options Discussed? *Pediatr Crit Care Med*. 2016;17(2):110-120.
12. Moseley KL, Church A, Hempel B, Yuan H, Goold SD, Freed GL. End-of-life choices for African-American and white infants in a neonatal intensive-care unit: a pilot study. *J Natl Med Assoc*. 2004;96(7):933-937.
13. Zakim D, Braun N, Fritz P, Alscher MD. Underutilization of information and knowledge in everyday medical practice: evaluation of a computer-based solution. *BMC Med Inform Decis Mak*. 2008;8:50.

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SILENCED SUFFERING IN SECOND TRIMESTER PREGNANCY TERMINATION

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The evolution of prenatal diagnosis and obstetrical practice over the last 50 years has improved the safety of women and infants in astounding ways, making possible vastly improved outcomes for both mothers and babies. But it has also presented parents with the need to make decisions of tremendous complexity and moral quandary about their children's wellbeing, through the option of pregnancy termination in the second trimester for genetic or medical disease.

Wellbeing is the operative word here, the one that engenders the head-spinning sense of dislocation parents feel upon being asked to make a decision either to continue their pregnancy, knowing their child is likely to experience disability or death, or to terminate their pregnancy, with the goal of sparing pain and suffering for their child.

This article explores the unique challenges experienced by these parents, the significance of clear and empathic communication by medical personnel, and the critical foundation this communication creates for parental recovery from the loss of their child.

Few would dispute that the prenatal testing and intervention now available allow parents to make decisions that spare suffering and respect the fundamental goals and values of their families. But the fact remains that in ten or twenty years, when genetic diagnosis is available far earlier in pregnancy, parents and health care providers alike will look back at this time and marvel at the brutality of the experience. To have to decide about ending a cherished pregnancy when that pregnancy has often been progressing without problem until well into the second trimester indeed poses an impossible dilemma for parents, a dilemma that forces them to weigh every aspect of what it means to be a parent.

Life or death—it's your choice.

This is the crux of the termination paradox—that parents in their dedication to their baby's wellbeing must decide whether or not to end their baby's life. If, in the exercise of their duty as parents, they believe they are acting in a manner that should be antithetical to the values of parenting, what kind of parents are they? The cognitive dissonance and crushing confusion many experience as a result of this paradox contaminate the already dreadful prospect of losing a beloved child. As a result, the normal course of grieving may be derailed, with guilt and shame predominating instead.

Genetic counselors and obstetricians make heroic efforts to protect parents from the starkness of this paradox with language that tries to blanket and buffer the harsh truth. But the medical blandness of terms such as “negative outcome” or “the procedure” or “pregnancy interruption” is lost on parents who recognize only “our baby” at risk. The child already invested with nicknames, personality characteristics, and a future is not so easily surrendered to well-intentioned medical reframing. What these parents hear is a question about whether they should actively decide to end their baby’s life. Or as some cry with anguish — “to murder my baby? What kind of mother does that?”

The concept of infanticide in our culture evokes the deepest and most disturbing reactions, arising from the violent contradiction between our reverence for the profound attachment between parents and children, and what is surely its exact opposite—child murder. Images of Medea and the Trojan Women come to mind, mothers who violated these sacred norms in their desperation and derangement or, in modern terms, women in the darkest thrall of postpartum psychosis.

Unfortunately, only rarely do these fears find expression in the counseling appointments and second opinion consultations that follow the diagnosis. Because many people, including caregivers, cannot name the painful conflict that underlies these decisions, the counseling and planning required for “treatment” are conducted in medical terms. The discussions are science-based and require rational understanding and assessment. Parents must then select among the objective data to engage in a new and excruciating examination of their life values: How much disability is too much disability? How do we speak for our baby’s rights? What is fair to our other children? How do we know we aren’t making the wrong choice?

But often the deeper process, the need to make reason of love and love of reason, is too confusing and distressing to articulate.

The searing pain of this process is intensified by the need to decide about the mode of ending their baby’s life—induction or dilation and evacuation (D&E). Having made a decision that feels antithetical to their ideals of parenting, parents are then required to confront another that feels even more overwhelming in its very specific physicality.

To add to this terrifying swirl of pain and fear and grief, many parents are affected by the toxic atmosphere in the United States around abortion rights. For some couples, their own faith practices may be sharply critical of abortion, and disclosure to other family members or friends that they are considering termination risks bitter condemnation. Even in a staunchly pro-choice environment, silence may seem the safest course, reinforcing in parents the sense they are somehow complicit in a crime.

Faced with this imbroglio of science, ethical and religious quandary, and passionate attachment, parents have several choices. They can hew to the line of science and intellect and try to minimize the emotional component of the decision. They can throw medical input to the winds and make their decision on mostly emotional grounds. Or they can struggle to

incorporate logic and love into a decision that best reflects their own values and goals and deal with the consequences as best they may.

What are these consequences?

Those parents who choose to continue their pregnancy often have access to increased social support and validation as the knowledge their baby's health is compromised is shared with family and friends. But parents who choose the privacy of termination are often denied the social support that facilitates normal grieving and are left with a lifetime burden of unresolved loss.

Some parents soldier on in silence, hoping that time and perhaps the birth of a medically uncompromised baby in the future will help them heal. But for those who do seek support, the solace they need may not be available.

Pregnancy loss in general—from miscarriage in the earliest weeks up to demise shortly before full term delivery—does not always receive the care and attention it deserves. It is often a private event, but even when the pregnancy has been public knowledge, the loss is sometimes minimized or even dismissed. “You’re healthy, you can have another baby.” “Be happy you didn’t have time to get attached.”

No one would dream of saying “you can have another six-year-old” to a grieving mother or father, but babies in these condolences are treated as somehow interchangeable. In fact, the death of an “invisible” baby whom no one knew, whose life was all about future and not past, imposes an additional layer of loss on grieving parents. When your only memorabilia for your child are ultrasounds and footprints and blurry pictures, the reassurance that luckily you don’t have more memories serves only to dismiss your grief, thereby increasing your sense of estrangement from the world around you.

For grieving parents following a termination, their worry about social disapproval combined with their internal conflict about the active role they had to play in their child’s death further complicates the loss. Lacking external validation and internal surety, their grief may be smothered by guilt and their suffering rendered invisible.

In recent years, obstetricians, genetic counselors, hospital social workers, nurses, and chaplains have done much to try to help relieve parents’ guilt and restore their damaged sense of parental competency. Memorialization practices that validate and honor the existence and loss of the baby are now routinely offered. Where in the past the “products of conception” would have been treated as “medical waste,” families are now provided with local mortuary referrals. Hospital chaplains offer blessings when requested. Parents are encouraged by staff to consider seeing and naming their child, and nurses and OBs make footprint cards for all babies, including those delivered by D&E.

In addition, online support forums such as aheartbreakingchoice.com and local support groups specifically for late termination offer the safety of peer reassurance. The excellent “A Time to Decide, A Time to Heal” by Molly Minnick (Pineapple Press, 2012) is often provided by hospitals and genetic counselors, offering information to help parents navigate the emotional and practical challenges they will encounter. For parents battered by the news of a compromised baby and isolated by the decisions they have had to make, these resources help to reinforce the integrity of their parenthood and to destigmatize their choice.

But important though these interventions are, they may fail to address directly the stark paradox of the termination. In its delicate imprecision, the language we use at times creates confusion where it seeks to clarify. As caregivers, we may be so conscious of the pain we are inflicting that the temptation to soften our language through circumlocution, euphemism, or determinedly clinical language is acute.

But these evasive linguistic tactics do not lessen pain; they instead convey the clear message that the reality is too terrible to be talked about. The opportunity to identify and untangle the guilt parents feel—that this guilt is in large part a result of the medical moment we live in and not their parental failure—is lost.

If instead, in all discussions with parents, the special circumstances that make this moment so uniquely painful are identified from the onset as clearly as the deviant strands on the errant chromosome, or the lethally high hypertension, a critical breathing space is created for parents. This space allows them, if they choose, to safely acknowledge the real weight of this decision with trusted medical professionals, thereby receiving essential reassurance about the integrity of their actions.

In addition, this space has the advantage of capturing all parents, not just the ones who choose additional counseling. Thus, for example, the determinedly data-driven couple who refer to even a twenty-three week fetus as an “embryo”—whose goal is to erase this painful experience as quickly as possible because they feel the loss is too terrible to acknowledge—are still provided with reassurance from respected sources, without having to reflexively reject the dangerous minefields of “counseling.”

A simple statement of understanding and compassion at the onset can have a powerful impact going forward: “We recognize with you that you are facing something that many generations of parents before us never had to deal with. We know that this choice you are facing between life and death may feel like a contradiction to your role as a parent. It is not. Your intention is to do the best thing you can for your child in an impossible situation and we know that whatever decision you make will be made from your best judgment. We will respect and support you throughout.”

This reassurance in the diagnostic and treatment period amplifies the power of subsequent mental health treatment because it aligns with the core goal of therapy: the detoxification of the haunting legacy of guilt and failure parents may otherwise experience. The open

acknowledgment of the factors unique to their experience, especially when it is building upon a similar discussion by the OB or genetic counselor, allows them to fully appreciate the complexity of their ordeal and to rebuild their shattered sense of parental competency.

Several important issues potentially complicate this rebuilding in therapy. The mental health practitioner or grief counselor who sees patients following termination is bound by the same need for precise and empathic language as the medical provider. Initially, however, the parents' language itself may be imprecise or vague because of their difficulty acknowledging their conflict. As a result, the therapist or grief counselor who follows up with these parents needs to be aware ahead of time about the special circumstances these patients have faced. If, for instance, the therapist is not herself familiar with the delivery choices patients must make, her efforts to elicit exactly what the couple has been through may inadvertently create additional pain in those who are not yet trusting enough to disclose the totality of the experience.

At the same time, the premature acknowledgement by the therapist of the decision dilemma at the heart of the patient's pain may overwhelm those for whom this issue is not yet safe to articulate. In this, as in most therapy dilemmas, if the therapist follows the patient's lead with respectful and nonjudgmental encouragement, he will eventually create the safety needed for full disclosure.

In addition, it is critical that therapists be very clear in their own beliefs about this polarizing topic and able to offer support that is genuine and understanding. Parents will sense ambivalence or disagreement about their choices immediately and the therapy will not only fail but create additional suffering.

Another not uncommon therapeutic issue arises from the fact that not all parents are routinely offered the same information or interventions at diagnosis, because of differences in medical practice and practitioner comfort. The parent who was gently but firmly encouraged to have a D&E by her OB may be distressed to learn, at a later date from a support group or online forum, that others benefitted greatly from the opportunity to hold their baby after induction. This sense of secondary loss may detonate renewed grieving about the decision, with a further collapse in self-esteem.

By recognizing and legitimizing this secondary sorrow, the therapist may be critical in helping the parents consider alternate ways to memorialize their baby. If no memory box was provided in the hospital, for example, the creation of one might be meaningful in assuaging their fear that they did less for their child than they might have. The "sometimes other parents have found this helpful" formulation presents the idea without endorsing it, thereby respecting the decisions already made, while opening up the possibility for expansion.

At times parents present for therapy who have already made what to them are non-negotiable decisions about how they will handle this loss—not naming the baby, for example, or creating any remembrances—but who are seeking therapy to eradicate the pain they continue to feel. To the therapist's eye, it might appear that re-negotiating some of these decisions would in fact

be helpful, but again the impetus for this shift needs to come from the parents. There is no formula for recovery, and the therapist's unwavering respect for individual decisions validates and bolsters the sense of parental autonomy which may have been devastated by the experience.

Over time, the bitter recrimination, "We did a terrible thing," evolves into the profound recognition, "We were challenged in a way few parents ever are, and we brought to this challenge all the love, strength, and integrity we have to make the best choice for our baby."

The memory of this lost child, released from guilt and blame, can then remain alive with parents down the years, as all lost children do, grieved and cherished for what was and might have been.

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HOW TO HOSPITALIZE A CHILD RECEIVING CONCURRENT HOSPICE CARE

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The landmark pediatric end-of-life legislation known as Concurrent Care for Children (CCC) authorizes state Medicaid Offices to provide children, who are less than 21 years old and living with a six-month prognosis, with hospice care and subspecialty care (1). This benefit ensures that parents are never forced to decide to stop life-prolonging therapies in order to receive quality care at home from an interdisciplinary hospice team focused on comfort.

Prior to CCC, hospice care and subspecialty care lived in relative peace and harmony. Once the intensive interventions being offered by the subspecialist could no longer achieve the child's and family's goals, there was a break in the service and payment structure to the subspecialist. The hospice then would become the new provider. Today these worlds collide and hospices along with subspecialists are treading in uncharted and undocumented territory. They are no longer mutually exclusive.

A simple concurrent care case example is a child, living with cancer and a six-month prognosis, who is entitled to continue chemotherapy once enrolled in hospice care. Child and family goals of care are now more complicated as comfort is combined with "services for the terminal illness" (1). A typical CCC care plan is complex and must factor in uncertain disease trajectories given rarity of some illnesses and limited studies, complex chronic conditions requiring many subspecialists to assist in management, difficulty delineating differences between comfort and life-prolonging entities of the care plan, and complications from medications and treatments.

Now layer on two different and distinctly unique care model payment approaches—hospice and subspecialty care. Hospice is paid a per diem to cover all the end-of-life needs of a child's terminal illness, while the subspecialist is paid through a managed care arrangement or fee-for-service to treat the child's illness. As these two worlds collide, bridging subspecialty and hospice care together, we are treading in uncharted and undocumented territory with extremely limited guidance from state Medicaid Offices. CCC is not so simple. In fact, it is clear as mud.

Let us step into the mud and see how a child receiving concurrent care might be hospitalized. As a case example, a child with relapsed rhabdomyosarcoma is at high risk for developing an acute episode of uncontrollable epistaxis (nosebleed) due to thrombocytopenia secondary to chemotherapy being used to prolong life, and will require a consultation with otolaryngology to stop the nose bleed. The child is admitted to the hospital. Who is responsible for providing care and receiving payment for this care? It could be the hospice. We know that hospice patients can be admitted to the hospital for general inpatient care and the hospice will still care, coordinate, and pay for the service even in the hospital. The hospice receives a modified per diem for this care. However, hospice inpatient care is often for acute and uncontrolled episodes of pain or other symptoms at end of life such as shortness of breath. In our case, the child is admitted because of epistaxis due to thrombocytopenia caused by chemotherapy, which is unrelated to end-of-life pain or symptoms. The oncologist typically admits the patient and bills for services rendered daily. The other subspecialists who consult such as otolaryngology would also see the patient and bill for services rendered. Within a concurrent care model, Medicaid pays the hospital for all services rendered during the hospitalization (i.e. embolization for epistaxis, oncology daily care, medications provided, etc.).

You may be asking yourself, should the hospice be paid during this hospitalization because the child is not at home receiving hospice or in the hospice facility? The answer is YES. Both the hospice and subspecialist are providing care and both should receive payment. The hospice nurses still need to coordinate care between the subspecialist, consulting physicians, hospital, and hospice team. The hospice spiritual care providers still care for the family and siblings during these uncertain times. The hospice social workers still work with families to ensure they receive the benefits to which they are entitled. Hospice care continues, but it may be over the phone or at a distance (We know about virtual hospice now because of COVID-19) (2). Hospices provide care coordination, symptom expertise and continuity of care during a hospitalization, especially for children admitted to low-resourced hospitals, which may lack pediatric palliative care teams.

For many state Medicaid Offices, however, this whole transaction is complicated and outside their traditional claims processing experience. There are typically no guidelines for how Medicaid should address these hospitalizations, so all too often they are audited, investigated, and/or denied. These Medicaid responses to concurrent care have translated practically to hospices discharging patients who are hospitalized and then re-enrolling once discharged. Our research has shown that children are three times more likely to be discharged while living from hospice compared to adults (3). In our experience, this is a terrible message to send the child and family who often interpret these actions as either hospice abandonment or false promise of recovery. In a situation where the child, family, and providers are under stress at end of life, managing hospital claims should not make matters worse.

To improve the process, we recommend the following 7 steps to hospitalize concurrent care children, based on clinical experience and emerging best practices:

1. Codify definitions and terms (e.g., life-prolonging care) so all key stakeholders have a common lexicon (4).
2. Engage proactively with the state Medicaid Office at the onset, even as early as initiation of hospice care to set communication expectations, train on concurrent care, and share care plans (5).
3. Confirm and document payment agreement between hospice, subspecialists, and Medicaid Office and document (6).
4. Clearly define and document roles and responsibilities between the hospice staff and subspecialist including care coordination (7).
5. Provide training on pediatric CCC care for families, subspecialists, and hospice team members.
6. Advocate for a Medicaid Concurrent Care Navigator to be assigned to the concurrent care children—preferably someone with clinical expertise such as a Registered Nurse (RN) (8). This position could bridge the gap between clinical practice and payment, while engaging with the hospices and subspecialists in care planning meetings and discussions to improve continuity of care (Figure 1).
7. Develop and document the plan of care for concurrent care children with both the hospice and subspecialist (6,7). Update this evolving plan of care regularly with documented sign-off from hospice, subspecialist, and Medicaid administrator.

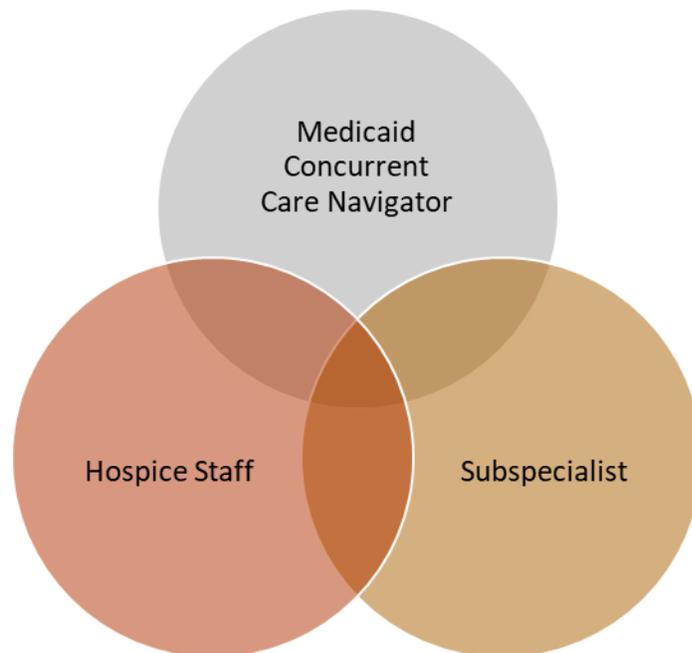


Figure 1. Recommendation for role of Medicaid Concurrent Care Navigator

In summary, Concurrent Care for Children is currently the only federal legislation that addresses hospice care for children. Although it has been available for children and families for a decade, there are still issues in implementation. Hospitalization under concurrent care is a glaring example of the much-needed modifications and reforms (9). Our recommendations for

improving hospitalizations for these children is an initial step in ensuring quality care at end of life for children and their families.

Funding Note: This publication was made possible by Grant Number R01NR017848 from the National Institute of Nursing Research. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the National Institute of Nursing Research or National Institutes of Health.

References

1. Govtrack.US. H.R. 3590--111th Congress: Patient Protection and Affordable Care Act. 2009. Available from: <http://www.govtrack.us/congress/bill.xpd?bill=h111-3590>. Accessed May 6, 2010.
2. Ellis K, Lindley LC. A virtual children's hospice in response to COVID-19: The Scottish experience. *J Pain Symptom Manage*. 2020; epub.
3. Lindley LC, Keim-Malpass J. Quality of pediatric hospice care for children with and without multiple complex chronic conditions. *Int J Palliat Nurs*. 2017;23(5):112-9.
4. Washington Medicaid. Hospice Services Billing Guide. Available from: <https://www.hca.wa.gov/assets/billers-and-providers/Hospice-bi-20180501.pdf>. Accessed August 25, 2019.
5. Utah Medicaid. Provider Manual Section Two Hospice Provider Manual. Available from: <https://medicaid.utah.gov/Documents/manuals/pdfs/Medicaid Provider Manuals/Hospice/Hospice.pdf>. Accessed August 17, 2019.
6. Indiana Medicaid. Hospice Services. Available from: https://www.in.gov/medicaid/files/hospice_services.pdf. Accessed July 11, 2019.
7. Michigan Medicaid. Provider Manual. Available from: <http://www.mdch.state.mi.us/dch-medicaid/manuals/MedicaidProviderManual.pdf>. Accessed July 30, 2019.
8. Lotstein D, Lindley LC. Improving home hospice and palliative care policies. *Pediatr*. 2019; 144(2): e20183287.
9. Lotstein D. Concurrent care isn't enough: More hospice reforms are needed for children with serious illness. *J Pediatr*. 2020; epub.

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Trusting Them with the Truth: Disclosure and the Good Death for Children with Terminal Illness.
Hannah L. Kushnick. *American Medical Association Journal of Ethics*, 12(7):573-577; July 2010

This article is open access available at <https://journalofethics.ama-assn.org/article/trusting-them-truth-disclosure-and-good-death-children-terminal-illness/2010-07>

Summary: This is a wonderful commentary with a topic that is pertinent to this issue of the eJournal. Speaking with children about their impending death is fraught with tragedy, a sense of the “waste of life,” and the desire to make the death as “‘good’ as it can be.” Ms. Kushnick reviews the benefits of talking with the child about the impending death. From the parent’s viewpoint, there is little regret and the bereavement process is less complicated with such communication. What research is available supports the notion that children are aware that they are dying. Attempts to “protect” the child by withholding information may be perceived by the child as insincere. Conversations with the child must be done in a developmentally appropriate way. Understanding the process may help decrease their fear. For adults, a “good death” is one that supports choice, enhances comfort and dignity, and allows for leaving a legacy. Do children deserve less? Hopes can be supported such as hopes for meaning, comfort, connection, and enjoying the time available. Thus, informed and supported, children can find meaning in their deaths, and this frequently involves altruism. This altruism might take the form of helping others through participating in research trials, doing something good for another person, or leaving a legacy or gifts to friends or family members. Such conversation with dying children shows them respect and allows them to make meaning from and have some control over the process: “telling them the truth and trusting them with it.”

Who is the audience for this information? This topic is pertinent to health care providers, support staff, parents, and the broader community.

What is special about this article? In four pages, clear information is presented to support the awareness by the child of his/her impending death, the benefits to both the child and parents of talking to the child about his or her impending death, and the capability of the child of dealing with the information.

Where and how can I apply this information? Health care providers and support staff can use this to inform parents in guiding conversations with their dying child. Parents can feel

comforted that it is in both their and their child's best interests, and they can help their child have a "good death." Extended family, friends, and the broader community can understand that, while sad, a "good death" of a child is possible.

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ITEMS OF INTEREST

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

1. NHPCO Palliative Care Online Resources:

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

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

Palliative Care Programs and Professionals

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

[Individual Palliative Care Membership](#)

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

2. Pediatric Hospice and Palliative Care Resources:

- **CaringInfo**, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. www.caringinfo.org

- *When Your Child is in Pain*
- *Talking with Your Child About His or Her Illness*
- *Talking to Your Child's Doctor: When Your Child Has a Serious Illness*
- *When a Child Dies: A Guide for Family and Friends*
- *Helping Children Cope with the Loss of a Loved One*

- **NHPCO's Palliative Care Resource Series** includes pediatric palliative resources such as:

- *Communication Between Parents and Health Care Professionals Enhances Satisfaction Among Parents of the Children with Severe Spinal Muscular Atrophy*
- *Consideration for Complex Pediatric Palliative Care Discharges*
- *'Who You Gonna Call?' Men with Duchenne Muscular Dystrophy Discuss End-of-life Planning*
- *Songs of the Dying: The Case for Music Therapy in Pediatric Palliative and Hospice Care*

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

3. Trends in Pediatric Palliative Care Research

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

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

4. Pediatric Hospice and Palliative Care Training:

- **[Upcoming 2020 Webinars provided by the Pediatric Care Coalition:](#)**
 - **August 20, 2020** – Pediatric Concurrent Care – with Lisa Lindley, University of Tennessee
 - **September 22, 2020** – Explaining Pain: Pain Education and Mind-Body Tools for Pediatric Chronic Pain – with Rachel Zoffness, American Association of Pain Psychology
 - **October 22, 2020** – Through the Eyes of a Grieving Child – with Viki Jay, NAGC – National Alliance for Grieving Children
 - **November 17, 2020** – Partnering with Funeral Professionals to Support Families Following the Death of a Child – with Kristin James, Greater Illinois Pediatric Palliative Care Coalition and Kelly Manion, Funeral Service Foundation
- The [2020 Interdisciplinary Conference](#) is going to be a virtual offering this year. While we look forward to a time when we can re-convene the NHPCO community face-to-face, the NHPCO staff is exercising its creativity and imagination to deliver a virtual event different from anything we have done before!

The Virtual Interdisciplinary Conference will take place over the span of three weeks, October 12-30, 2020. The conference will include live and on-demand content; there will be more than 60 hours of content, falling within 7 learning tracks, as well as opportunities to network and connect with your colleagues from across the country and NHPCO staff, and download resources that you can view off-line.

- ### 5. A new storybook resource for families.
- We are so grateful to also introduce you to Gerbert, a brave little gosling who helps children and their families process and discuss illness. Gerbert's egg hatched due to the need for bibliotherapy resources:

<https://www.ncbi.nlm.nih.gov/pubmed/28346862>

“Gerbert the gosling is strong and brave and has fun times with his family and friends but knows that, one day soon, he won’t be able to keep up with them anymore. As Gerbert prepares for his final migration, he finds a way to show his flock that he will always be with them. Includes a one-page Note to Readers and an online Note with additional information useful for parents, caregivers, grandparents, siblings, and teachers.”

<https://www.amazon.com/Gift-Gerberts-Feathers-Meaghann-Weaver/dp/143383023X>
<https://seattlebookreview.com/product/the-gift-of-gerberts-feathers/>

- 6. Subjects and Contributors for Future Issues of This E-Journal.** We are currently discussing topics such as self-care for future issues in 2020. If you have any thoughts about these or other topics, contributors, or future issues, please contact Christy at Christina.Torkildson@bannerhealth.com or Ann at ann@here4U.net.

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