

***Glimmers of Hope in Pediatric Palliative
and Hospice Care***

ISSUE #65 | NOVEMBER 2021



Pediatric E-Journal

PEDIATRIC ADVISORY COUNCIL

Released in collaboration with the National Hospice and Palliative Care Organization



NHPCO
National Hospice and Palliative
Care Organization

Photo courtesy of Karen Henrich and Mason Henrich.

Pediatric e-Journal

Pediatric Palliative and Hospice Care

Issue #65; November 2021

Issue Topic: Glimmers of Hope in Pediatric Palliative and Hospice Care

Welcome to the 65th issue of our Pediatric e-Journal. The impetus for this issue came from wanting to end this year with a collection of stories of hope and inspiration. After more than a year and half living with COVID, we felt you, our readers, were so deserving of being lifted up from the heaviness of this pandemic and all that it has brought to your lives, personally and professionally. This issue, therefore, offers a collection of articles that we expect will stimulate discussion about glimmers of hope experienced by professionals, volunteers, and family members as a result of their involvements in pediatric palliative and hospice care. Some who are unfamiliar with the realities of pediatric palliative and hospice care have said that these services must be morbid and depressing. The testimony of contributors to this issue provides an effective rebuttal to such views. As a result, we believe the contents of this issue will provoke fruitful reflection about the realities of hope in its many and varied forms as it is experienced in pediatric palliative and hospice care and in your own lives. May these stories encourage all of us to move forward with optimism that the future is bright. If our families can find hopefulness in the midst of challenging, medically-complex journeys with their children, may we follow their lead.

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

Comments about the activities of NHPCO's Pediatric Advisory Council, its e-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are currently discussing topics like sustainability, bereavement, sibling support, and standards for our four issues in 2022.

We are particularly concerned to invite contributions for articles on Sustainability. Let us explain.

The first issue of 2022 (#66) of the NHPCO Pediatric eJournal will be on **Sustainability**. In three decades or so, the ChiPPS Newsletter, then the ChiPPS e-Journal, and now the NHPCO Pediatric e-Journal have never had an issue focusing on this topic. Why? We think that several factors have led to this. First, in the early days, there simply weren't enough pediatric palliative care (PPC) or pediatric hospice programs to make any generalizations. Second, there are still many very different ways that programs with varying foci sustain themselves. Thirdly, sustainability

isn't a very warm and fuzzy topic. Who likes to think of the grubby realities of MONEY in these noble causes? Yet supporting the existence of our programs is crucial to providing palliative and hospice care to children/adolescents and their caregivers. Most of you reading this are part of a broader organization. **We are reaching out to you for contributions to Issue #66.**

What form might these written contributions take? Here are only some examples:

- A paragraph about how your program is supported
- An article about sources of support for your program
- Stories about how your program began and how the support has varied over time

What sources of support have you used and what are strategies that worked or were ineffective? Below are just some thoughts of possible topics:

- What models of care are most sustainable? Are you bundled with adult palliative care? With an adult hospice program? Does the parent organization support your pediatric services?
- What are the components supporting your bottom line? What are the income streams?
- Is your program supported by reimbursements for patient services? If so, what is your strategy?
- What are varying states doing to support pediatric palliative and/or hospice care?
- How do you justify your costs to your top executives? How do you approach your leaders who control the purse strings?
- How do you engage the public in seeking support?
- How can families help in seeking support?
- What charitable events do you host?
- What reimbursement strategies are most effective? What reimbursement strategies are least effective?
- How do you sustain your staff?
- If your organization did not survive, what lessons can you pass on?
- Feel free to tell us your personal story or that of your organization!

We are eager to hear from you! There are many ways that you can address this topic in addition to the above. If you have an idea, we are happy to collaborate with you in sharing your story. Target for submission of an article is December 1, 2021.

If you have any thoughts about Sustainability or any other topics, contributors, or future issues in 2022, please contact Christy Torkildson at christy.torkildson@gcu.edu or Suzanne Toce at tocess@gmail.com.

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

Produced by the Pediatric e-Journal Workgroup

- Charles A. Corr, PhD, Lacey, WA; Senior Editor
- Deborah Fisher, PhD, RN, PPCNP-BC, CHPPN, PANDA Palliative Care Nurse Practitioner, Children's National Hospital, Washington, DC
- Ann Fitzsimons, BS, MBA, Executive Director, here4U, Inc., Farmington Hills, MI
- Marta Friedman, LCSW, ACHP-SW, JD, Social Worker/Bereavement Coordinator, Complex Pain and Palliative Care Program (PACT Team), UCSF Benioff Children's Hospital, Oakland, CA
- Michelle Goldbach, Administrator/Director of Clinical Operations, Kindred Hospice, San Diego, CA
- Betsy Hawley, MA, Executive Director, Pediatric Palliative Care Coalition, Pittsburgh, PA
- Melissa Hunt, PharmD, Pediatric Clinical Pharmacist, Optum Hospice Pharmacy Services, O'Fallon, MO
- Nathan Ionascu, MD, Bioethics Consultant, Westchester End-of-Life Coalition, Westchester County, NY
- Rachel Levi, PhD, Licensed Psychologist, Private Practice, Oakland, CA
- Jennifer Mangers, MS, CCLS, Pediatric Program Manager, JourneyCare, Barrington, IL
- Jessica Sturgeon, MT-BC, Music Therapist, Seasons Hospice and Palliative Care, Middlebury, CT
- Suzanne Toce, MD, Retired Neonatologist, Gundersen Health System, La Crosse, WI; Co-Chair
- Christy Torkildson, RN, PHN, PhD, FPCN, Lead, MSN-Public Health Nursing Program, College of Nursing and Health Care Professions, Grand Canyon University, Phoenix, AZ; Co-Chair

Issue #64: Glimmers of Hope in Pediatric Palliative/Hospice Care

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

Hope is Not Cancelled

p. 7

We reprint this insightful paragraph as a reminder that hope can permeate even very dark times.

Lessons about Hope from Hudson

p. 8

Amy Sylvestre

In this article, Hudson's mother describes his battle with hypoplastic left heart syndrome. She recounts the ups and downs of their struggle, what it was like when Hudson's time on this earth became short, when he died, and afterwards. She insists that hope remains alive in their family.

Making It Count: Grief and Hope, Especially for Siblings

p. 11

Brittany Maldonado-Gosline

This author describes the impact of the death of her youngest brother at age 18 and how she was led to walk alongside grieving siblings as an advocate and mentor. From these experiences, she writes, “I learn much about my own grief, and what hope is. Hope changes, it changes like grief changes, it is nonlinear, there is no formula, hope is not a cure and grief never ends.” She adds, “I want grieving siblings to know that even when hope changes and it feels like it abandoned you and you feel a desperation to breathe, or an inability to move, and you beg for relief; I would like for you to know you will move through it. It may not look pretty, it may never feel ‘okay,’ but you will move through it and make it to the next moment. You will breathe again, and my heart is with you.”

The Other Mothers

p. 13

Debbi Simons Harris

The author of this article and her husband are the parent of three sons, the youngest of whom “had a Grade IV intraventricular and subdural brain hemorrhage at birth. Josh has multiple disabilities and complex medical needs.” In this article, she reflects on being a panelist to address family-centered care before an audience of hospital employees. What can she say “in the chaos that has become typical of our lives” by contrast with the other mothers on the panel and especially while her son is in the PICU and her husband is hospitalized in a critical care unit.

Lessons from a Bereaved Mother and a Bereaved Sister

p. 20

Oralea Marquardt, MSW, LCSW, and Kyla Marquardt

In this article, William’s mother and sister share lessons learned from his diagnosis at the age of 18 months with an ultra-rare neurodegenerative disease for which there is no cure or treatment option, his life and support from hospice care, his death at the age of eight years old, and their subsequent reflections.

Finding My People: A Teen’s Story of the Impact of Peer-Based Grief Support

p. 24

Samira Moosavi, CCLS

The author of this article is a children’s group coordinator at a California hospice. Here she tells the story of a girl who was bereaved by the death of her father when she was 13. The girl was initially very nervous about joining the teen support group, but eventually she became an active and enthusiastic participant. As she says: “At group, I found my people. At group, I found my ground.”

COVID’s Immersive Language: What It Teaches about Pediatric Palliative Care and Hope

p. 27

Dannell Shu, BFA, MWS

In this article, Levi’s mother (who has now become a parent advocate) reflects on the immersive language of the COVID pandemic era to show how many of the key terms in that language can be applied to families receiving pediatric palliative care. Examples from three child patients illustrate this issue’s theme of glimmers of hope.

Two of My Greatest Teachers

p. 34

Christy Torkildson, PhD, RN, PHN, FPCN

In this article, an experienced palliative care nurse and Co-chair of our Pediatric e-Journal

Workgroup reflects on what she learned from two young girls, a seven-year-old and a seventeen-year-old, as they faced illness and death. She writes, “Crystal and Tony demonstrated how you can find joy when facing the unthinkable. That no matter how young, you can have a legacy that will live on. They also showed us how important the work we do is, how being able to be present, truly listening, and walking alongside in their journey enriches not only our patients and families but also ourselves.”

Small Hopes from a Reluctant Zoom-er

p. 38

Hania Thomas-Adams, MC, CCLS

The author of this article openly confesses that when it comes to technology and social platforms, she is behind the times but is “OK with that and has no particular interest in catching up.” However, with the advent of the COVID era she “found myself sheltering in place at home and unable to see the patients that I work with. I am a Child Life Specialist working at a children’s hospital in Oakland, California. Everything about the work that I do necessitates human connection, and the power of this connection is the thing I value most about my job.” Strategies of avoidance only worked temporarily. “Eventually I knew that necessity and how deeply I missed my work with the kids would drag me in to Zoom and the world of telehealth.” Readers will want to know how this caring professional “was not dragged, but rather pushed in a pink stroller next to Mr. Peanut the stuffed elephant.”

Personal Reflection on 30 Years of Glimmers of Hope

p. 42

Stacy F. Orloff, Ed.D., LCSW, ACHP-SW

This personal reflection ranges from the author’s early service caring for a few ill children in “my work as a pediatric social worker at a very large hospice whose children’s program was mostly focused on healthy children of adult hospice patients.” Later, “as I was promoted into different leadership positions...I wondered if I would lose that sense of hope and wonderment. No longer working directly with our pediatric patients and their families, would I lose sight of moments in time which sustained hope to so many?” Several examples demonstrate why “the answer to that question was a resounding no.”

Glimmers of Hope: What the COVID-19 Pandemic Has Taught Pediatric Palliative Care

p. 44

Danielle Faye Jonas, MSW, LCSW; Lauren Cramer, MSW, LICSW; Jennifer Greenman, MSW, LCSW; Rachel Rusch, MSW, LCSW, MA; and Caitlin Scanlon, MSW, LCSW

These authors argue that “while the COVID-19 pandemic continues to be an incredibly challenging time to work in health care, this period has afforded the field of PPC the opportunity to consider ways to improve care and access to care for patients and families. These glimmers of light remind the field that by continuing to confront systemic racism, offering improvements for access to care, maximizing community building and professional development, and growing bereavement resources, the field can continue to grow amidst trials and tribulations.”

“Hope Gets Us Through Literally Every Day”: Strategies for Keeping Parental Hope Possible in Pediatric Palliative Care

p. 49

Jill M. G. Bally, RN, PhD, and Meridith Burles, PhD

According to this article, “Keeping hope possible involves four important processes including accepting the reality of their child’s illness, establishing control in some aspects of daily life, restructuring hope as needed across the illness trajectory, and maintaining positive thinking.” Further, “Strategies that care providers in pediatric palliative care settings can use to support parents include mindfulness; self-care and social support; celebrating milestones and creating legacies; and acquiring information.”

Finding Hopes When a Child Dies: How Can the Medical Team Reframe the Issue? p. 54
Suzanne S. Toce, MD

As a neonatologist, Dr. Toce encountered the death of a child patient all too often. In this article, she argues, “We need to reframe our concept of hope. When hope for cure or a prolonged life is no longer realistic, what are the hopes that are possible? Can we as providers help the parents and other caregivers conceive of smaller, more realistic hopes?” Using a case example, she illustrates the many glimmers of hopes on which providers can focus in caring for children and their family members.

Four Examples of Keeping Hope as a Priority p. 56
Jennifer Mangers, MHA, MS, CCLS; with contributions from Jennifer Leahy, LCSW; Jessica Harris, RN; and Megan Sizemore, Chaplain

Despite the “many changes that have impacted the patients and their families” in their pediatric hospice and palliative care program, these authors emphasize “one consistency we found was that patients, their families, and our staff kept hope a priority whenever possible...We always encourage our families to keep hope in their minds, but what we found so powerful was that one staff member or volunteer, one small task, or one verbalized wish could bring so much hope to so many people.” To illustrate “how our patients and families kept hope in the forefront of their minds,” this article offers four case examples.

Capturing Glimmers of Light through Photography p. 59
Karen Henrich and Mason Henrich

“Fifteen years ago, the non-profit Moment by Moment was established so that, through our lenses, we can capture the determination illuminated by children that have a potential life-limiting or chronically life-impacting disease or disorder. With a cadre of professional photographers in California, we have captured precious images of thousands of children and their families in both the children’s hospital and pediatric hospice settings, always at no charge to the family. Through these poignant images, it is evident that the spirit of a child does not hide in their illness. Instead, they radiate hope, courage, and an unbreakable connection with their families. We capture those glimmers of light that will provide indelible memories to share with others.” For those who may think it wrong to take photos at such difficult moments, “The simple answer: more than ever, [is that] families in these situations want to document and celebrate what they have this day, this moment...In the setting of our unique mission, we witness the capacity of photographs to act as expressions of love, objects of hope, and tools in the process of grief.”

HOPE IS NOT CANCELLED

“Hope is not cancelled
Love is not cancelled
Coping is not cancelled
Growth is not cancelled
Integrity is not cancelled
Learning is not cancelled
Gratitude is not cancelled
Kindness is not cancelled
Laughter is not cancelled
Connection is not cancelled.”

Original source unknown; reprinted here by permission from Gina Kornfeind, MSW, MS, and Ratna Behal, MD.

LESSONS ABOUT HOPE FROM HUDSON

Amy Sylvestre

Hudson's Mom

amysylvestre@gmail.com

www.amysylvestre.com

New Author: *Wholehearted Truth: A Devotional for a Heart in Pieces* (coming soon)

It seemed like just any another day in the cardiac unit as I rocked my precious baby boy, Hudson. I stared at his little round face, and he had his eyes fixed on me. I remember telling myself to hold tightly to this moment because I knew it was special.

Hudson and I were tucked away in his little pod, quietly soaking up our time together. Hudson's pod mate was having a hard day. Normally, I was asked to leave when the doctors and parents discussed each child's prognosis or critical care was administered. But this day, I was quietly rocking Hudson, and no one seemed to notice me.

I couldn't hear everything, but some of their words still ring in my ears.

"But there must be something you can do. Another surgery? Another hospital? Where can we go?" Her mama draped herself over her two-year-old daughter's bed.

The doctor, trying to convey the same message again, said, *"We have done all that we can for her. We believe her time is limited. You can stay with her."*

The conversation continued with whispered words that came across the room. The pleading for next steps. The confirmation that the next steps were palliative care and keeping her resting and as comfortable as possible.

Hot tears rolled down my cheeks. She wasn't mine, but I absorbed that mama's pleading, begging, aching as my own. It was a foreshadowing of my own journey with my precious, strong Hudson.

Five months later, these conversations were for my ears and my heart to process. "His oxygen saturation won't stabilize. He doesn't look as good today. We are concerned. He's not tolerating these changes to his body."

From the beginning, Hudson's battle with hypoplastic left heart syndrome was nothing short of his own private war. The beautiful music and hopeful lyrics of Hillsong's *Cornerstone* filled the room as Hudson surprised the doctors when he entered the world breathing despite fluid filling his lungs. He even cried a little. He continued to show his strength as additional challenges with his liver presented after open heart surgery.

Hudson showed tenacity and tenderness. Even though he was a baby, his personality filled the cardiac intensive care unit. The nurses loved him so much that they named him Huddy Buddy. It stuck and everyone started calling by their term of endearment.

We had weeks where Hudson would do well and show off in physical therapy, but then the next week, an infection would cause a fever and his heart would race. We watched numbers go up and down. The CICU became our home over those eight months, and we knew what all the beeps of the machines meant.

After Hudson's second open heart surgery, he was doing so well for about a week, but then everything went downhill.



Hudson

Hudson's wonderful daddy and I had just walked in the door from the hospital and my phone rang. The sentence I remember the doctor saying was, "We will try to keep him alive through the night." We sped back to the hospital to be by his side.

They moved us to a private room to spend the last few days with our boy. It didn't feel real, and we were living in denial. We tried to fit in a lifetime of "I love yous" and memorize Hudson's handsome cheeks and unruly, dark hair. We tried to tune out the beeps and the noise of the hospital. We were exhausted emotionally, physically, and spiritually. We begged God for our son. We begged doctors for our son.

It became clear that Hudson's time was short, and all the nurses came by to see him and say their goodbyes. We let our families know that Hudson's war was almost over. He had fought and fought and now he would be able to rest and be truly Hudson without pain or struggle. He would be with Jesus soon.

Just as Hudson heard "*Cornerstone*" when he entered the world, we sang it again for him in his last moments. His brave daddy sang over him and rocked him. Hudson was never alone. As we said, "See you later," he heard God's voice say, "Welcome, we've been waiting for you," as he entered heaven. He was in our arms and then in the arms of Jesus.

While we can rest in the hope that our faith provides, those same hot tears roll down our cheeks as I write about my boy. There is hope after outliving my son. We are one day closer to our son. There is life, laughter, holidays, vacations, and goals. There is much to be done with the rest of my days as a mom of child loss. It seemed like just another day in the cardiac unit as I rocked my precious baby boy, Hudson. I stared at his little round face, and he had his eyes fixed on me. I remember telling myself to hold tightly to this moment because I knew it was special.

There are glimmers of hope all around our family. We experience the healing presence of God personally and we lean on others as we need support. We offer a shoulder to moms and dads who have also outlived their children. We acknowledge the profound, enduring impact child loss has on a family while also showing others the way out of the pit of despair. I share my scars and stories of my boy.

While life can feel bittersweet without our missing piece, the sweet is even sweeter than before because of Hudson. His life changed mine. Tears will come. I will miss my son all of my days, but I will also pursue dreams and goals in honor of him. We belly laugh as a family, and we have cake on Hudson's birthday. We celebrate big and we soak up our family and friends.

I'll always be Hudson's mama, and I intend on making him proud. I give myself permission to really grieve. Each year around the day he passed away, I schedule days to just be Hudson's mom and think about him and let the tears come.

I also give myself permission to live. To really live and enjoy this life God has given us. No one can take Hudson's place in our lives, but we can run after things that matter and impact the world around us. We can choose to step close to those who are grieving and to offer hope.

It is fitting to share with you about hope as a family that spent so much time at Children's Hospital of Philadelphia. Their slogan is, "*Hope lives here.*" We desperately held onto their hope for our Hudson.

That hope is not gone.

As Hudson's family, we can say the same for our house.

Hope *does* live here.

Because of Jesus.

*Please reach out to me for support if you also are navigating the loss of a child. It is too hard to grieve and hope alone. The valley is too deep to walk by yourself. I'm here.

-###-

MAKING IT COUNT: GRIEF AND HOPE, ESPECIALLY FOR SIBLINGS

Brittany Maldonado-Gosline

Deputy Director/Directora Adjunta

Co-Director Grief Support/Co-Directora de Apoyo de Duelo

Jacobs Heart

Watsonville, CA

brittany@jacobsheart.org

My family is one for the books. It is large, loud, loyal, and loving. It is the greatest gift of joy and pain in my life. And together, we experienced grief like nothing else. On September 23, 2013, we lost my youngest sibling, Corbin, to APML (Acute Promyelocytic Leukemia, a subtype of [acute myeloid leukemia](#), a cancer of the white blood cells) at the age of 18. Corbin was/is a warrior of all things good and fought fiercely for four difficult years. He was the youngest of six and very well versed in making sure we knew he learned from ALL of his older siblings' mistakes and how to make the best of it! Corbin DID make the best of his far too short life. He lived boldly and loved ever so deeply and was not afraid to show it. He left me with a guiding light to make the best of it and make it count and love with all you have. With his brightness leading me, I have found my way into advocacy and mentorship for grieving siblings and while I walk alongside them, I learn much about my own grief, and what hope is. Hope changes, it changes like grief changes, it is nonlinear, there is no formula, hope is not a cure and grief never ends.

What does it mean then to live boldly and love deeply with the life you have? After I lost Corbin, this question burned through my mind and heart often, and still does, as making it count also evolves as my perspective, healing, and awareness grow within grief, and certainly things came along my way I didn't expect. Whether these things come from Corbin I will not know, although it sure feels clear to me that it does. Because of him, I am dedicated to bringing hope to other siblings like myself in all that I do, even in writing this article. I want grieving siblings to know that even when hope changes and it feels like it abandoned you and you feel a desperation to breathe, or an inability to move, and you beg for relief, I would like for you to know you will move through it. It may not look pretty, it may never feel "okay," but you will move through it and make it to the next moment. You will breathe again, and my heart is with you.

Moving through and finding hope again, sometimes moment to moment, means something different to every griever. For me it means that even in the pain and desperation somehow you find a way to make it count. You find a way to smile at somebody, you find instant connection with a fellow griever, and even without words you feel a shared comfort in knowing each other's pain. In that moment you gave each other hope to make it to the next without even knowing. Hope is there when you may not see it. Hope got you through the next inhale, otherwise why would you take that breath when grieving so desperately. Hope led you to exhale, and if you keep the pattern going, one day at a time, all of a sudden without knowing it,

you're making it count. Through hope you begin to live a little more boldly, you take a walk, you call a friend...you slowly may even love a little deeper because you get it. You find that stranger to smile at, you have that instant connection with someone who is new to grief. You are living like Corbin, making it count, living boldly, loving deeply, unapologetically. Hope has the chance to get you there; breathe it in.

-###-

THE OTHER MOTHERS

Debbi Simons Harris, MA, MS, GCAS-Creative Writing/Narrative Medicine

Joshua's mother

Debbisimmonsharris@gmail.com

Hi. My name is Debbi. My husband and I are the parents of three boys. Our youngest was born at 31.8 weeks. He had a Grade IV intraventricular and subdural brain hemorrhage at birth. Josh has multiple disabilities and complex medical needs.

I hear myself repeating this unlikely mantra for the hundredth time, and it comes as easily as though I were selling makeup or leggings or cookware. It is early morning, but the room is dark for its lack of windows. Dozens of employees slump into hard conference room chairs, clutching Styrofoam cups of hot coffee, hoping the session will end sooner rather than later. The room is warm and sticky, and the faces staring back at our small panel of parents are blank, bored, or sleep-deprived.

The event seeks to enliven the mission, a human resources innovation facilitated by a local hospital. New hires—doctors, clerks, housekeeping staff, and everyone in between—are introduced to the institution's mission and vision through the experiences of real live families. A well-versed facilitator launches a PowerPoint presentation extolling the virtues of family-centered care. From our perch behind the folding table, we three parents shift in our seats, scanning the crowd for signs of life.

We are the families of frequent flyers. Our children have been admitted to the hospital so often that, once stabilized, the rest of the stay becomes an odd sort of social event. We greet primary nurses like family and enjoy warm exchanges with our favorite medical assistants and support staff.

My name is Debbi, and I am a trach mom... I practice various opening lines in my head, searching for a new angle, a lead-in that might perk up this weary crowd.

Families are the experts, the constants in the child's life... The facilitator is listing the principles of family-centered care. We parents sit up straighter in our seats with each point, like star athletes. Some of the audience members drift further away, in a collective slump. It's awfully early for a lecture.

Hello there! I'm Debbi and I am so happy to be here today!

I continue the silent rehearsal of my introduction. This audience needs a jolt, a parent with lots of charisma, full of energy.

Not me. I'm too tired.

In the chaos that has become typical of our lives, I have spent much of the past two days at my husband's bedside, first in the ED, and then the critical care unit of the adjoining adult hospital. Our roller coaster never stops. A sick boy, and now an ailing husband...

* * *

"Deb, something's wrong." Victor had awakened me late in the night, a couple of days before. His eyes reflected an eerie sheen, and his forehead was slick with sweat. I had never seen him so afraid. *Heart? Blood pressure? Glucose?* A career Marine, Victor is in superb physical condition for his age, but the effects of exposure to Agent Orange in Viet Nam continue to deliver worrisome health concerns.

"We're going to Emergency," I said. I had learned with Josh's many visits that I was treated more respectfully, taken more seriously, if I dressed professionally, slapped on some lipstick, and combed my hair. I repeated the routine, begged Josh's night shift nurse to keep an eye on the other two boys until I returned and led Victor to the car.

Hi, my name is Debbi! My husband and I are the parents of three boys. Well, my husband is in critical care right now, and I don't know what's wrong with him. Two nights ago, I sat worried and freezing by his bedside in Emergency in a stupid denim skirt—with lipstick on—as the staff administered test after test. I knew as soon as the nurse placed an IV with a Heparin lock that we weren't going home. I really hoped the daytime nurse would show up for my son at home. What day is this?

My imagined introduction is shaping up poorly. The man facing me in the front of the audience supports his head precariously on one arm. He holds his mouth in a boorish smirk, and both legs are spread carelessly into the aisle. Eyes half-shut, he makes no pretense of his desire to go to sleep. The facilitator's voice has devolved into a monotonous buzz as she moves mechanically from one PowerPoint slide to the next.

Hi, I'm Debbi, and I think the parent panel is doomed.

The first parent is finally introduced. The poor lighting in the room casts a gloomy half-shadow over his face, and the employees shift restlessly in their seats. The anxious father speaks enthusiastically about his child's medical journey, but the heavy mood does not lift. I think the crowd might just want us to die, so they can go to lunch.

Hi! My name is Debbi and I so happy to be here! My husband is upstairs in critical care, and our youngest boy—we have three sons, you know—is next door in the pediatric intensive care unit.

I don't know why I'm here, except that I promised the facilitator when she asked me some weeks before, during the rare twenty minutes that life was calm. Several hours after my

husband was transferred to critical care—stable, but still awaiting diagnosis—we were discussing what to do with our two older boys during this emergency when my cell phone rang.

“Josh doesn’t seem right.” It was the new home care nurse. “His trach secretions are copious and thick. He’s febrile, and he can’t stop coughing.”

The new nurse is young and doesn’t know Josh yet, but I trust her assessment. It is viral season, and children with complex respiratory histories and exposed airways are at highest risk for illness. A call to the pulmonologist determines the course of our next few days. I am to return home immediately to pick up Josh and deliver him to the PICU as a direct admission. I arrange for an older church lady who lives nearby to care for our other boys. While home, I grab medication lists, back-up tracheostomy tubes, lullaby tapes, clothes, a curling iron, and a toothbrush. I spend days running the long hallways that connect the two hospitals to make certain that my husband and child receive proper assessment, reasonable diagnoses, and adequate treatment. I am exhausted.

“Hi, I’m Debbi. My husband and I have three boys. The youngest has Muscular Dystrophy—”

They have introduced me and I am caught off guard. I have heard myself repeat this practiced introduction countless times—for conferences, panel discussions, committee meetings—and Joshua’s medical history and assorted diagnoses usually roll off the tip of my tongue. But I think I hear myself say Muscular Dystrophy, and that’s not on the list.

“Oh, wait! Did I say that our youngest has Muscular Dystrophy? No, he doesn’t!” I throw my head back and let out a hearty laugh. The audience remains quiet, uncomfortable. I muffle my roar to a soft giggle, and explain.

“I don’t mean to make light of anything, but I am just so tired. My husband is very sick, upstairs in the Critical Care Unit, and my toddler, who has complex medical needs and multiple disabilities, is next door, in the PICU. I have been living in the hospital for days, and I’ve come here to you from the adult hospital upstairs. Two of our boys have been in the NICU, so we know everyone there. And our oldest has had Scarlet Fever, meningial encephalitis, and a strange immune deficiency reaction. The cashier in the cafeteria keeps giving me the employee discount, no matter how often I tell her that I don’t work here. I can barely remember where I have left our other two boys, and talking so much about this frantic, ridiculous, joyful life has done nothing to make it normal to other people.”

But we’re alive and together, and that’s everything.

Much of the audience comes alive then, likely thankful for a bit of levity and appreciative of the candor. The stretched out, sleeping man remains unresponsive, but I decide it doesn’t matter. I let the employees know how important their roles are to families like mine, and the facilitator introduces the next speaker, a striking, curly-haired blonde who reminds me of Barbie.

I catch significant parts of her extraordinary story between the animated sighs and gasps of the now lively group of employees.

“Hi, my name is....My husband and I have six children...

Six children? How does she do it and still manage to look absolutely marvelous!

“One of our children has a major heart defect and has had countless surgeries. The other has a neuroblastoma.”

No!

“The doctors could do nothing about the tumor, so we decided to treat our child through an extremely disciplined diet. Both are doing very well.”

I should have stayed upstairs.

“Everyone here knows us. One day, I was coming down the hill from the parking lot, and the baby threw up on me. In shock, I accidentally let go of the stroller, and the other kid began to roll down the hill!”

The impeccably dressed mother laughs and the audience roars.

“But two nurses rescued the stroller, grabbed the vomiting baby, took me inside, cleaned me up, and wiped my tears away. This is such a wonderful place!”

Hi, I’m Debbi and my son has a trach and a feeding tube, and a wheelchair, and an oxygen concentrator, and an oximeter, and a feeding pump, and a ventilator, an occasional PICC line, and a cough assist machine, and...

We are all considered the *uber* parents. We devote ourselves to our children and their seemingly impossible medical conditions and demonstrate our gratitude for their lives by volunteering every spare moment to the hospital that saved them. We want to nurture understanding—if that will help heal them, or simply ease their pain and ours—and inject the hearts of anyone who will listen with a bit of empathy, understanding of our realities, and compassion.

Hi, my name is Debbi. My husband and I have three boys...

* * *

Early on, I resolved to make this new, unanticipated life worth living, to normalize this roller-coaster world for my precious family, and to tell our story the only way I knew how. The sacrifices have assured that money is in short supply. Vacations are few—and those we do set

about require the organizational skills of a career Marine, three months of strategic planning, and the additional financial expense to carry along two home care nurses. I find myself peering into the mirror from time to time, wondering how the thin skin around my eyes has become so dark, forgetting the exhaustion of too many open nursing shifts, almost three cumulative years of my husband's active-duty deployment as the boys entered their teenage years, and the profound sadness of a difficult diagnosis of a beloved parent and becoming part of the sandwiched generation of caregivers. Friends easily fall by the wayside, unable to keep pace with what they see as a life defined by despair, and unprepared to celebrate the new, minuscule things we've chosen to define our joy. But I find that faith and hope often emerge in a stronger way when at first pressed down by adversity. I learned that from my mother.

I see my mother now only in my dreams. This time, we sit together in a large stadium. My weary head rests on her shoulder. The silkiness of her black hair brushes against my forehead, and I feel safe. We pay little mind to the grand antics taking place on the wide field far below us. The participants there are like dolls, or puppets, their performance of little consequence to us here.

"Would you like to stand, Mama?" I ask. "I don't mind standing, if you'd like." My mother is grand, elegant, and profoundly articulate. In this moment, she is funny.

"Oh, no," she replies. "Where I am now, we stand all of the time. Part of that whole dominion thing." I snuggle in and we talk. I tell her about my life. The boys. I don't tell her about Papa, how sad he is, and how his deep well of grief leaves no room for ours.

A song I love says that heaven is real, life is a dream, and I am caught somewhere in between. The day after my mother died, I felt the soreness of a thick dagger, straight through, from the front of my heart to the back. I could not move without the heaviness and sharpness of the imaginary blade announcing its presence. My spirit wept unceasingly, and the sorrow took my breath away. I wanted to find her, this woman who had given so much of herself to me, to assure her happiness and well-being in this new realm, an unknown world just a heartbeat away, but still so far from my mine.

But my mother is eternally and immutably mindful, even in death. She enters my life in profound ways, other than my dreams, through sweet, caressing messages left in the books, cards, and notes she so carefully scripted while she still could, her beautiful handwriting stretched across each page like priceless works of art. Mama was my cheerleader, a nurturer, the Great Encourager. She believed in me and in my writing. She quietly knew it would make my life, save my life.

"We kept everything you wrote," she told me once, her voice soft and full. "When you were little, we were so amazed with what you could create at such a young age."

Sometimes I am drowning in my fishbowl. I am crushed by the tenuous nature of my life, and I cannot breathe. Creativity becomes an elusive foe, and I cannot write. I begin to clear the

cluttered physical spaces of added responsibilities—substitute matriarch, hostess, and facilitator—to make a place for a writing life among the busyness of my motherless world.

I straighten stacks of old books, sort through tangled strands of jewelry, and fold brightly colored summer dresses into a cardboard box to make way for the coldness of winter, and room to hone my craft. I think about Mama, and what she might say to me now, how she would smile, her dark brown eyes twinkling at sight of Josh's progress. He's twenty-one, Mama. Imagine that! He cried out when you left us, against the physics of his tiny tracheotomy tube, he called for you as your spirit flew.

My hands run across an old calendar: Baby's First Year: Your Guide to a Happy and Healthy First Year with Baby. I remember how sad I was so many years before as I set aside the dubious gift, devastated that the richly colored stickers to mark typical milestones would likely never be used. Two decades years later, I pull it closer, examine its pages. I smile now at the parenting tips—finger foods, stranger anxiety, ear infections—and warm at the sight of fading scribbles on the cover, love notes from the family, welcoming its tiny new member whose head swells with an abundance of fluid, and whose skin hangs from malleable, barely formed bones, like crinkled parchment paper.

Mama has facilitated the intervention against a life of pity and despair. She has set the tone for inclusion of this strange, fragile person. Her note hangs prettily in the upper left corner of the otherwise unmarked calendar, surrounded by autographs from siblings and cousins who had just learned how to write, and others who followed her lead, etching polite introductions, hopes, and blessings.

I read Mama's note and weep tears of gratitude for yet another prophetic gift:

1/11/93

Hi Joshua,

You won't remember our conversation, but you and I had a long talk with God and each other. You're going to be a real blessing to our family. We love you very much.

Oma

Fresh with the renewal brought by the deluge of tears, the gift of this unexpected emotional release, I take my place in the corner of my newly organized, lovingly dedicated creative space, and begin to write.

** * **

I'm Debbi and I'm a trach mom. This is my whole life. Is it enough?

The new employees are all ears now. They are captivated by the courage and vigor of the other mother. I watch her grace, and strength, contemplating my own frailties, and I am ashamed at the need for comparison. We are a rare element, a unique category of families, and we share the same kind of pain. But the stress of our lives often makes that too easy to forget, and the isolation leaves us hungry for attention—and validation.

The presentation comes to a natural pause as the other mother bends delicately and searches for something in her tote bag. The audience hesitates, their anticipation is palpable. They are fully invested.

What more could there be?

The other mother emerges from her search with a kittenish smile and a glossy covered paperback.

“If you’d like to know more about my life,” she says at once proudly yet humbly, “you can purchase the book I’ve written at any local bookstore.”

At the end of the other mother’s presentation, the crowd gathers around her, eager to greet such an extraordinary woman. I take a few steps back to give her more room. A copy of the book lays on the table, its shiny back cover glimmering under the subdued lights. A photo of the happy family shows eight smiling faces amid a yard of perfectly manicured greenery. They wear matching outfits.

Hi, I’m Debbi and I’m a trach mom. I contemplate the soothing sound of familiar words, grab my shabby mismatched purse and head upstairs, first to critical care, then to the PICU. Feeling just as blessed as every other mother.

*Halfway between heaven, and the uncertainty of earth,
A child hangs in limbo for the promise of its birth.
A veil holds back the darkness, the certainty of death
As a mother cries for nothing more than to feel the baby’s breath.*

-###-

LESSONS FROM A BEREAVED MOTHER AND A BEREAVED SIBLING

Oralea Marquardt, MSW, LCSW

William's mother

Licensed Clinical Social Worker

Treasure Coast Hospice

Ft. Pierce, FL

OMarquardt@treasurehealth.org

and

Kyla Marquardt

William's sister

On January 9, 2007, my second child, William, was diagnosed at the age of 18 months with an ultra-rare neurodegenerative disease, Gm1 gangliosidosis. There is no cure or treatment option for Gm1 and most children diagnosed with the infantile form of the disease die by the age of four. Our family enrolled William into hospice care at the age of two and, with the care provided, he was able to remain at home and outlived the prognosis of his disease. William died surrounded by family on February 13, 2014. He was eight years old.

My oldest daughter, Kyla, was five at the time of diagnosis and was thirteen days shy of her twelfth birthday at the time of William's death. The impact of William's illness and death on Kyla was always one of my chief concerns as a mom. My experience led me to becoming a Licensed Clinical Social Worker. I now work in the field of pediatric palliative and hospice care and am passionate about supporting siblings of our pediatric patients. Since William's death, Kyla and I have ongoing conversations about the sibling experience to enhance the work that I do. Kyla has become an advocate in her own right, sharing her story at conferences and through various platforms with the hope that it will increase knowledge of the sibling experience and will help other siblings of children diagnosed with life-limiting conditions.

Recently, I sat down with Kyla, who is now nineteen and enrolled in her second year of Chemical Engineering at the University of Florida, and we reflected on the years caring for William, his death, and the grief that followed. Our conversation focused on three key elements: the impact of William's illness on each of us individually and as a family; support we found and what helped; and how our wellbeing and relationships changed in meaningful ways.

Diagnosis Day and the Aftermath

I vividly recall my sweet little boy playing happily on my lap while a geneticist informed us that he would slowly lose his abilities, one-by-one, and ultimately die. Each moment of the fateful day that our family now refers to as "D-Day" is etched in my memory. My husband and I drove

the two hours home from the doctor's appointment in silence. My mind was in a fog, yet at the same time consumed with questions and thoughts. How was I to care for him? How would I know what to do and if he was comfortable? This was not how I imagined our life to be. My heart was breaking. As we arrived home, we were immediately greeted with a big hug by our 5-year-old daughter, Kyla. My immediate thought went to her wellbeing. How were we going to tell her that the brother whom she adored was going to die? How could we support her while dealing with our own grief? I wanted with all my soul to protect her from the hurt that would accompany the pending losses. My heart broke once again.

In the months that followed, I was consumed with navigating a complex medical system, specialists' appointments, and learning more about Gm1. At the same time, William's caregiving needs were increasing, and he was not sleeping. My husband and I were working in shifts to care for him while simultaneously trying to keep life as "normal" as possible for Kyla. Eventually, we contacted our local hospice agency for help. The hospice team embraced our family and for the first time since we received the diagnosis, we felt hope. The hospice team guided us in developing our philosophy of care and assisted us in addressing William's ever-changing physical needs. There was a sense of relief that we were no longer doing this alone.

Kyla's experience was much different. This is what she remembers most:

I cannot recall the details of when I learned about William's diagnosis and prognosis, but Gm1 became a common word in my day-to-day life. I knew that William was different from my friends' siblings. I was aware that Gm1 would cause my brother to die, yet it was hard to really comprehend. What I truly remember was the feelings I felt as William's disease progressed.

My biggest struggle when William was alive was the feeling of loneliness. Our house was in constant motion with nurses, social workers, and chaplains. While the nurses and my mom were almost always at home, they were often busy with William, and I did not want to disturb them while they had bigger issues. I also struggled with making friends as I had trouble relating to kids my age who had "normal" childhoods. I spent much of my childhood entertaining myself.

Finding Support

Along with addressing the medical needs of William, hospice provided a volunteer to sit with him so that my husband and I could leave the home and solely devote our attention to Kyla. They also provided counseling to attend to our anticipatory grief needs. The counselor that my husband and I met with gave us the space to express and process our feelings. She also gave us guidance on the language to use to talk to Kyla about her brother's illness and offered strategies to support her. Kyla met individually with her own counselor. I was thankful she had someone outside of the family system who could help her process her own feelings as I was worried that she was hiding her feelings from us.

After a while, Kyla began to express that she did not want to continue with counseling. I was adamant that she continue because I found it so very helpful for myself. My counselor advised me to let Kyla take the lead of what she needed and to give her an element of control in a situation where she had none. She also alerted me to behaviors that may present that would indicate a need for counseling to resume. It was tough for me to take this advice, but I did, and through Kyla's recollection of that time, I now recognize the importance of doing so.

I was five when I entered counseling with hospice. Looking back, I can appreciate how the counseling laid the foundations of asking for help and expressing my feelings. However, as time progressed, I grew tired of talking about William and my experience connected to him. I wanted to be recognized for who I was, individually, and not have my identity to be only as the sister to William. It was my hobbies and my parents' support of my hobbies that helped me the most while William was alive. Music, martial arts, and even school were all endeavors that gave me the spotlight, and successes that my family could praise me for. I enjoyed constantly focusing on the tangible and being able to improve myself and my skills.

Growing with Grief

After William's death, I continued counseling and immersed myself with patient advocacy activities. Kyla stated she did not want counseling or to continue with the fundraising and awareness events that she initiated while William was alive. Again, my instinct was to force her to do both because I found both were helpful to me as I grieved. However, I remembered the advice to empower Kyla with choices. I recognized the importance of allowing Kyla to find her voice and develop her own narrative of her experience.

Meanwhile, Kyla turned to the activities that she began while William was alive to cope with her grief.

When my brother died, it was my music that helped me cope. I was able to stop focusing on the eerie silence that now permeated my house, instead filling it with the melodies of my choice. I fell in love with repainting the world around me in sound, to be able to lose myself in the universe for even just a few moments. I carried myself with a new purpose that has stayed with me throughout the rest of my life.

When Kyla turned fifteen, she began to talk more about William and was ready to return to counseling to process her grief and share her experience with me. I will be honest; the narrative of Kyla's lived experience was sometimes hard for me to hear because it brought to the surface how much she had endured. In supporting Kyla in her grief, I had to be vulnerable, be willing to examine how I parented her, and acknowledge the times while she was growing up where I was not emotionally present to attend to her needs. As hard as these difficult conversations were, I knew they were essential and a pathway forward in our healing as a family. I believe that our family's bond is stronger because we learned how to communicate with one another. Learning how to acknowledge and validate each other's feelings and having open, honest, and difficult

conversations continue to serve us time and time again as new challenges in life occur. I like to think of this growth as a gift from William. Kyla defines William's gift to her in this way:

It is hard to tell exactly how my life was changed by William because he was such a core part of my childhood. His life impacted mine in almost every way imaginable. I feel that I have grown up to be a more empathic and compassionate person because of my experience. In teaching me the power of music, William taught me the value of living with passion, of focusing on personal development, and of occasionally surrendering myself to serenity. The most important thing William taught me was personal resilience. William, for whom every day was a struggle, showed me that humans can endure so much more than we may initially perceive possible. His ever-persisting smile and happy glow are some of the strongest memories I have of who he truly was, and despite everything, he never failed to make us laugh. Growing up with a brother like William made me realize that no matter how bad the circumstances, I have strengths and resources that allow me to get through times of adversity.

-###-

FINDING MY PEOPLE: A TEEN'S STORY ON THE IMPACT OF PEER-BASED GRIEF SUPPORT

Samira Moosavi, CCLS

Children's Group Coordinator

The Elizabeth Hospice

Escondido, CA

samira.moosavi@ehospice.org

Lilly, age 17, shared with us the impact of having peer-based, grief support services for herself and her family. She has participated in The Elizabeth Hospice's Camp Spero Teen Camp Council to support in shaping the camp experience for future campers and continues to advocate for those that are grieving in her community. She has also given permission to share her story in this article.

Peer-based support groups offer a safe space for children and teens to find validation, connection, community, comfort, and support. According to Kilmer et al. (2014), the context of the group can help youth feel connected and supported. This allows them to draw from the collective experience and wisdom of others. The peer support, validation, and normalization experienced in the groups can provide a fruitful environment for helping children and teens process and integrate the loss into their lives. This can help them feel more hopeful about the future, experience compassion and caring, and develop empathy for others' circumstances and pain.

The Elizabeth Hospice is a leading provider of grief support to children, teens, and families. The mission of The Children's Bereavement Program is to provide a safe space for participants to share their grief story, honor and memorialize their loved one, and connect with peers in the community. In addition to peer-based grief support groups, the program offers school-based programming, a summer grief camp (Camp Spero), and crisis intervention for students and faculty.

My grief journey is never going to end. That's something I have accepted. But where I am today—from where I was—is very different in a very good way.

When you lose someone you love, your whole world is flipped upside down.

My dad died from a sudden heart attack when I was 13 years old. I never thought something like this would happen to someone I love so much. Having to go through it is almost too hard to explain or put into words. For a while, I didn't know what to do. I felt so alone. I couldn't find people I could relate to. There wasn't anyone I could talk to about my feelings. I couldn't talk to

my friends who had their parents and were still going through their life stuff. At such a young age, it was a lot to also put my grief on them.

About a year after my dad's death, I joined the Children's Bereavement Program at The Elizabeth Hospice. They offer peer-based grief support groups for children and teens in the community. At group, I found my people. At group, I found my ground.

In the beginning, I was really nervous about participating in the teen support group. But everyone was super welcoming. I listened to their stories and realized that the other group members were going through the same thing I was. I made connections and friendships. I found people I never thought I could find. I began working through the process of how to heal—even though I realize I may never fully heal. Group is a great environment to truly be yourself and tell people how you feel. I found this really refreshing. I felt like in a way, I could breathe.

Nowhere else is like this space. Discussing grief is not something commonly talked about in our world. In group, it's a common thing. Having these types of conversations make me feel normal and validated. To create a safe space for people to tell their story, to go through what they are going through, and to find people to connect to can be life changing. Having group has brought me a sense of peace. It is truly magical to find a group of people who embrace your story and help you grow as a person for the better.

In group, we lift each other up through the hard times—birthdays, anniversaries, and holidays like Father's Day. Some of my best friends are the ones I made in group. These bonds will stay with me throughout my life.

Now that I have community, I want to help other kids who are grieving find community too. I reached out to the leaders on my high school campus to bring grief support to my school. I have learned that one in five children will experience the death of someone they love before reaching the age of 18 (Doka, n.d.). That means about 500 students at my school alone could be grieving. These kids might not have the resources I had to help them through this. I want other kids to feel supported and loved, and to have a safe environment where they can share their thoughts, feelings, and worries. I am hopeful and inspired to bring the same support I received to others.

I know my dad would be very proud of me for being an active participant in the Children's Bereavement Program. And he'd be as thankful as I am for the program. Not just because of the way it's helping me but because it's also helping my mom and our family work through our grief.

Something that brings me hope is knowing that life is different and continuing in a way that I can only grow from here.

References:

1. Kilmer, R., Gil-Rivas, V., Griesse, B., Hardy, S., Hafstad, G. S., & Alisic, E. (2014). Posttraumatic growth in children and youth: Clinical implications of an emerging research literature. *American Journal of Orthopsychiatry*, 84(5), 506–518.
DOI:[10.1037/ort0000016](https://doi.org/10.1037/ort0000016)
2. Doka, K. (n.d). Editor of *OMEGA, Journal of Death and Dying*.

-###-

COVID'S IMMERSIVE LANGUAGE: WHAT IT TEACHES ABOUT PEDIATRIC PALLIATIVE CARE AND HOPE

Dannell Shu, BFA, MWS

Levi's Mom, Parent Advocate

Pediatric Palliative Care National Task Force

MN Palliative Care Advisory Council, Pediatric Palliative Care Coalition of MN

dannell@mamashu.org

Even if it's just a little thing, like a song, there's still that sort of common language, that common denominator we can all relate to.

Jonas Carpignano, filmmaker

In March 2019 it took only seven days for our Minnesota community to go from life as we knew it to near complete shut down as a result of COVID-19. My family and I were rattled by the quick succession of change and didn't for a moment believe this was going to be over by summer. Instead, we found ourselves getting reacquainted with an old family friend: Uncertainty.

Uncertainty first showed up in our lives in the form of an unspoken diagnosis when our son Levi was born in 2009 with severe brain damage. He was given hours to days to live. We were first time parents, in shock and disorientated by the NICU rhythms, now facing the pending death of our child. Two weeks later we met a pediatric palliative care team in preparation for bringing Levi home. By the end of the week, Levi arrived home as Uncertainty tagged along, becoming an unwelcomed house guest. Little did we know then, our life with Levi would last seven years and Uncertainty would become a close family friend.

Since my son's death, I have been running a business where I meet 1:1 with clients training them to build physical and soulful resiliency. Two weeks into the pandemic I began to recognize my clients were asking many of the same questions and experiencing many of the same emotions as families whose child has recently received a diagnosis for serious illness, medical complexity, or are facing a transition to hospice care.

It was a lightbulb moment! This was when I began to recognize the connections between living in a pandemic and caring for a child with medical complexities. The skills I had learned while caring for Levi within our in-home ICU for seven years were the same skills I was training my clients to develop.

Throughout the pandemic I have been continuing to have lightbulb moments. Conversations with families who are living in this pandemic while also caring for a child with medical complexities have further enlightened these insights. Conversations with pediatric palliative

care and hospice providers as I serve alongside them locally and nationally as a parent advocate have shed light on their pandemic experience.

Families with a child with medical complexities often talk with each other about how difficult it is to put into words their lived experience, even to close family and especially to providers. This easily leads to misunderstandings and aloneness. As much as I wish the pandemic had never happened, I feel deeply hopeful about the opportunity it has given us now to bring light to the felt and often unspoken challenges families face.

COVID's Immersive Language

Lived experience is a powerful teacher. In 2014, I began serving as a Parent Advocate in pediatric palliative care and hospice. One of my roles is to build bridges between families and providers. To improve communication, understanding, education, and advocacy in both directions. The COVID-19 pandemic has given families and providers a unique and shared lived experience that is reshaping us as people. We are in a vibrant and exciting moment in history. There are many bridges we can build from this that will be of help to all of us as we work together to provide the best possible care and quality of life to children who are living with serious illness, medical complexities, and/or facing their end of life. For example, consider for a moment what *relentless* and *fatigue* meant to you before the pandemic. Now consider how the pandemic has changed your lived experience, put these words together *relentless fatigue*, and transformed your understanding to be both known and felt in multiple aspects of life. This change is the gift I'm speaking of. It has brought you into the world families live every day.

One enormous gift COVID-19 has given us is a new shared language: social distancing, shelter in place, quarantine, pods, long hauler, contact tracing. We have experienced new layers of uncertainty, isolation, fatigue, survival, and being understaffed. The definitions of these words are deeply familiar to the children and families in need of palliative care.

The moment a child receives a diagnosis of serious illness or medical complexity, their family enters a pandemic. One that often endures for the rest of the child's life or until a complete remission has been established. Their daily experiences mirror what it has been like to live in the COVID-19 pandemic. Usually a family's pandemic life runs parallel to the rest of the community (including providers) living a "normal" life, which causes immense isolation.

The pandemic experience of having a child in need of palliative care goes unseen, unrecognized by even our closest friends and family. Families live in survival mode with relentless fatigue and exhaustion. There are never ever enough caregivers available to help. Parents are left to cover every open shift, easily for days on end, while juggling full time jobs and raising siblings.

This article is an opportunity to pause and build a bridge between our shared COVID-19 immersive language lesson and the ongoing realities families face daily, to shed light on the gift of this shared language. In this article you will hear about three children: Levi, Caden, and Isabel—all of whom are medically complex, tube fed, nonverbal, mobility challenged, and have an in-home ICU requiring an army of caregivers. First, let's briefly meet these amazing children.

Levi (my son) was born in 2009 with severe hypoxic ischemic encephalopathy and deaf/blindness. The oldest of two boys, he was an explorer who led us on a deep dive into western and eastern medicine. Levi lived 7 years and is known for being a teacher of relentless patience, savoring the tiny milestones, and living from your heart.

Caden, the youngest of five, is a 12-year-old boy born with Down syndrome and a heart defect. At 10 months he experienced a medical error during a routine procedure that caused brain damage and significant medical complexities. In the past four years he has experienced a succession of overlapping medical challenges. Caden enjoys ocean waves, swimming, music, swinging under trees, and family time. He is known for being a jokester, a determined warrior, a relentless overcomer, and a people lover.

Isabel was born in 2003 with a world of unknowns and uncertainty as a result of her brain not developing in utero. From a young age she easily made friends and savored summers on the lake at her family cabin. Isabel lived 18 years and died in 2021. She is known for her sneaky humor, an ability to modulate life's rhythms toward peace and calm, and being an attentive teacher.

Let's take a look at four new words that have arisen from the COVID-19 pandemic. First, we will consider their Webster definition (**) and their COVID context. Then we will apply this understanding to the experience of a family with a child in need of palliative care. As you read, my hope is for you to have your own lightbulb moments when your COVID experience connects with the families you serve.

A COVID Long Hauler is a person who experiences one or more long-term effects following initial improvement or recovery from a serious illness (such as [COVID-19](#)).** In many situations these individuals have tested negative for COVID-19, however they are experiencing unexplainable bouts of physical challenges which disrupt their ability to work and participate in family life. As a result, they have struggled to receive adequate diagnosis and subsequent support.

Within palliative care a **Long Hauler Family** includes a child living with a serious illness and/or medical complexities. Together they have been navigating a medical journey for one or more years. Very often around the one year mark a realization sets in that this journey isn't a sprint, it's a marathon, and we have to pace ourselves differently. There is great uncertainty and internal struggle about how long this will go on, particularly when the child is facing a shortened life. The family desires as much time together as possible yet endurance feels impossible. The medical journey impacts the child and every member of their family's abilities to participate in school, work, community, and family life. Depending on the child's diagnosis, city of residence, and available medical teams, their need for pediatric palliative care can often be overlooked or unmet.

“Finally, the world is waking up to our reality,” says Isabel’s mom, Amy. A Long Haul Family of 18 years, Amy has sustained pandemic life since the moment she gave birth. She has lost count of the number of times Isabel had been admitted to the hospital. Rather she marked time by the number of bedside nurses who befriended them and whom Isabel recognized.

Social Distancing is the practice of maintaining a greater than usual physical distance (such as six feet or more) from other people or of avoiding direct contact with people or objects in public places during the outbreak of a contagious disease in order to minimize exposure and reduce the transmission of infection.** During COVID, entire communities have been social distancing and these measures have often resulted in cancelling group gatherings, restricting travel, and working from home.

For Long Haul Families, social distancing is a way of life. The concern is less about spreading a disease and all about keeping their immunocompromised child protected from common viruses like colds, flu, and strep throat. For Levi, Isabel, and Caden, a common cold easily becomes pneumonia. Given each of their unique respiratory challenges, pneumonia always disrupts other body systems and without vigilant care becomes life threatening. This in turn disrupts plans and triggers PTSD as the level of care quickly escalates.

Social distancing impacts where and how these families can be a part of school, work, and community life. Relationships become strained as these families are not able to consistently participate. Plans are routinely cancelled at the last minute. Holiday gatherings, birthdays, and anniversaries are missed. Travel and vacations are completely redefined or skipped entirely – all the things COVID has caused for our entire country over the last 18 months. For Long Haul Families, this continues for years and years. It impacts parents and siblings as extensively as the child with medical needs. There is no break, no reprieve, no “getting back to normal,” no hope of a vaccine, and repeatedly what’s at stake is their child’s life.

A Pod is a small group of people (such as family members, friends, coworkers, or classmates) who regularly interact closely with one another but with few or no others in order to minimize exposure and reduce the transmission of infection during an outbreak of a contagious disease.** People reorganized their lives into **COVID Pods**, choosing like-minded friends and family to provide social engagement and the deepening of relationships in an otherwise isolating season. Many pods were formed around the need to share the load of managing children with online school while juggling work online. COVID Pods have been able to modulate their levels of isolation from the larger community as pandemic conditions have changed over time.

Unlike a COVID Pod, a **Long Haul Family’s Pod** is unchosen and centralized around their child’s medical needs. Individuals the family sees regularly (e.g., in-home caregivers, therapy providers, educators) become default pod members. Friends and family who provided support and social engagement soon after their child’s diagnosis often wane the longer the journey gets. Making connections with other Long Haul Families provides rare opportunities to expand their Pod and engage in critical social connections.

“Sharing life at a distance is a struggle,” says Isabel’s mom. Combining social distancing with pod-life for years on end takes its toll. Family relationships become strained as expectations of “normal life” can’t be achieved by Long Haul Families. Caregivers become the most consistent pod members. They are in your home at all hours of the day/night, accompanying you to clinic appointments, park outings, joining holiday gatherings and family trips.

“We are fortunate, some of our PCAs (Personal Care Assistants) have become like family and our biggest support system,” says Caden’s mom. In the best situation, caregivers and families enjoy sharing life together, while caring for the child with medical needs. They form lasting bonds with the whole family and become an integral support system when their extended family doesn’t participate in pod life. On other days, families are faced with impossible choices. When asked how a newly hired PCA was doing, one parent remarked, “My child doesn’t like her much, kindness doesn’t come easy to her, but I really, really need the help and there’s no one else available.”

Additionally, when a caregiver or someone in their household gets sick, they have to remove themselves from the pod and self-quarantine from the child until full health has been restored. The pod member who steps in to cover the missed shifts is usually the pandemic fatigued parent. Often there isn’t anyone in the pod who can step in and cover when a parent gets sick.

Contact Tracing is the practice of identifying, notifying, and monitoring individuals who may have had close contact with a person having a confirmed or probable case of an infectious disease as a means of controlling the spread of infection.* The COVID-19 pandemic has taught us to look both forwards and backwards in time regarding the individuals we come in contact with in in-person settings. We are repeatedly making decisions based on the risk of exposure to ourselves and others. We understand there is a direct ripple effect between an individual’s health and the impact it has on others around them.

For Long Haul Families, contact tracing is an essential skill. Foreseeing the potential risk of exposure to a cold can avert months of pneumonia. Every medical decision, big and small, made on behalf of their child requires advanced contact tracing skills. There are three significant ripple effects that impact the child, forward and backwards in time, when it comes to making medical decisions, most of which are never discussed in advance with providers.

The first ripple looks at how will the child’s quality of life change, for better or worse? It goes beyond the pros/cons discussion and looks at the larger impact. How will adding a new medication/a surgery/moving to a feeding pump change what my child will and won’t be able to experience this month/year as compared to last month/year? Caden is a kid who enjoys being outside, particularly basking in the sunshine. Only after his eye surgery did his family learn that his eyes would be permanently dilated, preventing him from being in direct sunlight. Although this is a possible outcome of this surgery, the surgeon made no mention of it beforehand. Caden has lost an important joy in his life and his parents weren’t given the opportunity to prepare him for it.

A second ripple effect is how a medical decision impacts the child's other bodily systems. Due to siloed specialization, providers often only consider medical decisions primarily in relation to their medical focus. However, what happens in one system can have a direct ripple effect into other systems, plus emotional and social aspects of the child as a person. Caden's eye surgery is again a great example. He went in with a stable GI system and came out with long term GI complications providers are unable to explain. Palliative care providers can be more likely to understand this ripple effect and provide a safe space for these conversations. By and large, families have little to no opportunity ahead of time to "contact trace" in this way. Instead, after a medical decision, parents are often chasing symptoms, drug reactions, and new challenges after the fact. They're trying to piece together what happened and chase down answers from siloed providers. They struggle to get coordinated help that addresses the intricacies of their child as a whole body, whole person.

The most often overlooked is the third ripple effect, the impact medical decisions have on the other members of the Long Haul Family. During the pre-op meeting for Caden's eye surgery, the doctor discussed with his mom, Lori, that he would need to lay on his back for several days and not touch his eye for four weeks. The well-meaning surgeon was completely unaware of what this would look like back home. Caden's care escalated to needing two people providing direct care 24/7 for four weeks. This already-fatigued mother was now the 24/7 default "second person" working tandem with his homecare team. "We could not leave Caden's side for even a moment. Not to fill his food bag or go to the bathroom," says Lori. Her only opportunity to sleep was when two other adults were caring for Caden. Additionally, for four weeks there was no capacity for anyone in the house to grocery shop, cook meals, do dishes, laundry, or clean. All activities for the whole family, other than the father's job and siblings' school, came to a screeching halt. As it happened, Caden had three eye surgeries in ten months requiring the same level of post-surgery care every time.

A significant number of medical decisions that impact Long Haul Family members are the ones that have an ongoing impact. For Levi this included decisions like shifting from bolus gravity drip feedings to using a feeding pump, to near continuous feedings at a slower rate. Related to this were the decisions about what to feed him. As his parents, this impacted not just the logistics of what it meant to feed our son. It also changed our emotional relationship to feeding him, the experience of family mealtime, when therapy could be scheduled, and what kinds of outings we could do as a family.

Room for Wonder

As we understand the COVID language through the lens of palliative care families, a hopeful space for wonder opens up. New questions begin to emerge.

- What skills and strategies have Long Haul Families developed to endure a sustained pandemic life for years on end?

- How can we reframe our challenges in a way that connects us more deeply to the people around us? When are expectations out of sync with what's possible?
- Who are the members of this child's pod? Are we providing meaningful care to all of them? As a provider, am I a trusted, active member of this child's pod? How could I/our team do better at this?
- What if families and providers had "contact tracing" discussions when considering medical options and decisions? How will this decision impact the child's quality of life, now and into the future?
- How does the decision impact the child's other bodily systems? What other providers need to be brought into the conversation?
- How are other members of the Long Haul Family impacted, short term and long term? What resources are needed for whole family sustainability?
- What if we revisited these contact tracing discussions weeks or months later to see how accurate the hypotheses were and adjust support as needed?

The Hope of a Shared Song

The COVID-19 pandemic has gifted us with new words and a powerfully shared experience. For many, this is a traumatic experience, one we are still struggling to navigate. It is messy, painful, and unrelenting. Lived experience isn't always the kindest teacher.

As we come to understand the families who have a child with serious illness/medical complexities as Long Haul Families, an internal anxiety can begin to soften. We are not alone; they are not alone. These pandemic veterans are immense resources for how to sustain social distancing, pod life, relentless fatigue, and the heartbreaks of life. Uncertainty has become a knowable partner in their life. They have developed skills for how to endure while cherishing the very act of surviving, one fragile breath at a time.

These families have been journeying ahead of us for years, singing songs many are only beginning to hear. I believe the common language of COVID has given us the capacity to hear these songs, hum along, and perhaps even join in on the chorus. As we sing, understanding, hope, and wonder will grow. Together we will discover a more resilient future.

-###-

TWO OF MY GREATEST TEACHERS

Christy Torkildson, PhD, RN, PHN, FPCN

Lead, MSN-Public Health Nursing Program
College of Nursing and Health Care Professions
Grand Canyon University
Phoenix, AZ
christy.torkildson@gcu.edu

To many, the idea of finding hope when faced with a terminal diagnosis in a child is incomprehensible. Yet there are many shared glimmers of hope in this issue and I expect in our readers experiences, as well. When we decided on ending 2021 with this “Glimmers of Hope” issue, I thought back to the children and families I have been privileged to work with. Unfortunately, there have been many, but with each child and family I learn how to better help others. I can’t share all the wonderful moments that gave me hope or demonstrated the experience of hope, but I hope you find hope in the following shared experiences.

Crystal was a 7-year-old little girl with a diffuse intrinsic pontine glioma or DIPG, a pediatric terminal brain tumor with a median survival of 9-18 months from diagnosis.¹ Children who have DIPG are usually cognitively intact, and Crystal was no exception. She had several friends she met through the brain tumor clinic and knew many of them had stopped coming to the clinic. She had also been to several celebrations of life of some of those friends with her mother.

Crystal knew her body was changing, with significant weight gain due to steroids, slow decrease in fine and gross motor control, and eventually difficulty swallowing. Her mother did not want anyone talking to Crystal about her prognosis unless Crystal brought it up or asked specific questions. Her mom could not bring herself to discuss her condition with Crystal. Crystal lived over two years from diagnosis, but she would never discuss her diagnosis—until one day in the garden.

As we (RN and Child Life Specialist) pushed her wheelchair through the garden, Crystal noticed the white and pink flowers blooming. She asked to stop so she could smell the roses and then turned to us and said, “You know my favorite color is pink.” Since we had had a very pink-themed unbirthday party just the week prior, we all knew pink was her favorite color. So we teased her and said we would never have known. She then stopped us in our tracks when she said, “I only want pink flowers when you celebrate me.”

This was the opening we had been hoping for. I simply asked, what do you mean, and quite simply and directly Crystal said, “You know after I die, when I’m all dressed up and people come to say goodbye, I want everything to be pink and my hello kitty blanket over me.” What followed was one of the most heartbreaking and powerful moments of my nursing career,

where a 7-year-old girl taught me about living each day, protecting the ones you love, and being true to oneself.

At her unbirthday party, Crystal had received an Easy Bake Oven© and lots of puzzles. She was extremely focused on putting the puzzles together with the help of our child life specialist and gluing them so they would not come apart and could be hung as pictures. Her Easy Bake Oven© also worked overtime and she baked cookies and then sold them along with the puzzles to all the staff and visitors. During the heart-wrenching conversation we found out that Crystal was planning on “making a lot of money so I can get presents for my sisters for birthdays and Christmas so they won’t forget me.” Through this we found out that her biggest fear was being forgotten.

During this time, Crystal knew that I traveled a fair bit and, in her words, “You talk to a lot of people and you always have your computer.” Acknowledging what she said was true, Crystal proceeded to tell us, “I think you should always show my picture, that way I know you won’t forget me, and you can let everyone know I was happy.” Sucker punch!!! She then proceeded to tell us which picture I was to use, and it is included in this article.

I don’t think I have the words to tell you how much this little girl taught me. After the initial gut-wrenching conversation, we would always end the day by talking about the things that were on her mind, be it her hamster or something else she had decided we should do for her celebration of life. To this day, I know that I, the child life specialist I worked with, and all our staff are proud that Crystal felt she could ask us anything and was never afraid—and we are still humbled by the lessons this little girl taught us.



Crystal

Tony was a 17-year-old girl who we met while she was in remission of her second bout of cancer about three years prior when she was referred to the palliative care team for support with reintegration to school and relationship building. Tony was upbeat, had a wonderful relationship with her mom, and had a best friend that she had known since pre-school. Tony had been dealing with cancer since the age of 12 and had gone through innumerable surgeries, chemotherapy, and radiation.

Tony relapsed about nine months after she was referred to palliative care. She and her mom followed the recommended course of treatment, which included more surgery, chemo, and radiation. Tony went into remission after a year of therapy. She was intent on graduating high school, planned on going to college, and then med school, and yes, focusing on pediatric oncology.

Unfortunately, a year later Tony relapsed again, the fourth time. She was admitted to the hospital and we met to discuss her goals of care, review her understanding of the treatment plan proposed, and to see if she had any questions. Tony did something she never had done before: she asked her mom to leave the room so we could talk in private. Her mom agreed albeit uncomfortably. Tony then informed us that she was not going to pursue treatment, that she had, “been there, done that, not doing it again.” She told us that she wanted to let us know about her decisions so we could help support her mom when she came back into the room and she told her of her decision. She did not want us to tell her mom or help her; her focus was on supporting her mom.

Her mom joined us, and Tony let her know her decision. Her mom, understandably upset, tried to convince Tony to try again but Tony was adamant. She then told her mom what she really wanted was to make memories, “like they (the palliative care team) were always recommending.” She wanted to use her college fund to go see all the places they had read and dreamed about while she still could, and she wanted to share her story so “others would know they have choices, and that palliative care is not about dying but being supported so you could live.” Humbling that this 17-year-old knew this when so many of our colleagues could not accept this!

Tony and her mom then met with the oncologist with the palliative care team to determine how to best treat symptoms while traveling. We connected them to palliative care teams throughout their journey and Skyped whenever there was a concern while they were gone. A “Go Fund Me” campaign was started with the help of the team’s social worker to help cover costs when the college fund ran out. Tony, her mom, and her best friend then traveled the U.S. and Europe for the next six months. Tony had a new lease on life and did amazingly well.

Her story was picked up by the local paper, then the national news, and she was invited to tell her story on one of the national talk shows on her return. Although weaker, she wanted to tell her story and, in her words, “let people know about palliative care, this is my legacy and maybe I can help another kid and their family find support.” Tony did just that, traveling to another state to be on the show and then sitting through several follow-up interviews where she was an

advocate for palliative care and having a say in her own care; again in her words, “Quality of life matters, not just the years of life; chemo, radiation, surgery are fine if they will bring a cure, but after three tries I am not going to be cured and I would rather sit here and be able to share my story, spend time with my mom and my best friend, and be happy.”

Tony died two weeks after that interview, at peace and surrounded by her friends, family, and the palliative care team, just shy of her 19th birthday. A young woman of conviction, courage, hope, and love.

Crystal and Tony demonstrated how you can find joy when facing the unthinkable. That no matter how young, you can have a legacy that will live on. They also showed us how important the work we do is, how being able to be present, truly listening, and walking alongside in their journey enriches not only our patients and families but also ourselves.

Reference:

1. Childhood Brain Stem Glioma Treatment (PDQ®)—Patient Version. *National Cancer Institute*. May 2016; <https://www.cancer.gov/types/brain/hp/child-glioma-treatment-pdq>.

-###-

SMALL HOPES FROM A RELUCTANT ZOOM-ER

Hania Thomas-Adams, MC, CCLS

Child Life Specialist

PACT Team, UCSF Benioff Children's Hospital

Oakland, CA

Hania.Thomas-Adams@ucsf.edu

With the exception of my partner's father and an elderly lady I know from the local coffee shop, I was the last person in my life to stop using a flip phone. I made it through college and my first year of graduate school with one, becoming something of a curiosity to my peers along the way. When I was eventually gifted a smartphone by my parents, I sat there in a state of reluctant tech evolution as my 16-year-old sister programmed the entire thing for me in 12.7 seconds, eventually prying it from her grasp as she tried to set up a Snapchat profile for me. ("No! I don't want that." "But EVERYONE has it!") She won that battle in the end; Snapchat being her sole form of communication required me to eventually download and learn it if I ever hoped to talk to her. I am currently in a similar standoff regarding Instagram with several people in my life and am so far unrelenting. When it comes to new technology and social platforms, I drag my feet. I read books that have covers. I subscribe to actual newspapers. I print out articles and take written notes. I am perpetually wishing that this e-Journal came in paper form. I am, as my sister said, Behind the Times. I am also OK with that and have no particular interest in catching up.

But of course, enter 2020. Approximately one year ago, life as we knew it got turned inside out and shaken, and I found myself sheltering in place at home and unable to see the patients that I work with. I am a Child Life Specialist working at a children's hospital in Oakland, California. Everything about the work that I do necessitates human connection, and the power of this connection is the thing I value most about my job. Kids make you work for it; they are masters at detecting a lack of authenticity and they let you in only after you prove yourself. In person, this often looks like direct eye gaze, a subtle scooting forward, a verbal invitation, or the more brazen plopping-down-on-the-lap. All of this requires a purposeful presence, mutual respect, and the quiet beginnings of earned trust. The pandemic, I feared, rendered this impossible.

When I first learned about telehealth and the Zoom platform, I reacted with doubt, hesitation, and no small degree of profound sorrow. This was not human interaction as I knew it or wanted it, and I mourned for the collective loss of connection. I feared Zoom would be isolating and ineffective and, as anyone who has ever tried to get a child's attention as they are looking at a screen knows, likely futile. I ended up spending the first month of the shelter in place volunteering for every possible administrative task that I could perform remotely that didn't involve Zoom, most of them including the development of written supportive material and activities for the kids at our hospital. This needed to get done and worked for a while, but I was running out of things to accomplish and (surprise!) the pandemic ended up lasting longer than

the initially proposed six weeks. Eventually I knew that necessity and how deeply I missed my work with the kids would drag me in to Zoom and the world of telehealth. I ended up being half right. I was not dragged, but rather pushed in a pink stroller next to Mr. Peanut the stuffed elephant.

The mother of a patient I had previously worked with reached out to me, asking if I could work with her daughter around an upcoming procedure she had scheduled. The little girl was fearful about the procedure and developing exaggerated fantasies about what it entailed while refusing to talk directly about it. The session would be over Zoom, and out of care for this family and respect for my need to Get With The Times, I said yes. I feared that I had no idea what I was doing, but at the proposed time I clicked on the link and was quite surprised when the little girl's face materialized in extreme close-up on my screen.

"Why hello!" I said. She said "hi" back, slightly shy and looking everywhere but at me. It had been a long time since we'd seen each other. I attempted to make conversation for a few minutes but only got shrugs and one-word responses. This was not going well and there was no use in pretending otherwise.

"Can I tell you something? This is the first time I've done this Zoom thing," I confessed.

"It is?" she said, startled.

"Yup. True story. And usually, I see you in my office, but today we're both in our living rooms. I don't even have shoes on. I'm just starting to learn this stuff."

She peeked at me. There was that eye contact.

"I know Zoom a lot," she said. "For school."

"Ah yes. Of course. Thank goodness we have an expert here."

Not used to being the expert on things, she smiled. "This is how you change your username and turn off your camera and go upside down," she said, showing me. "This is Mr. Peanut my elephant. And this is my cat." She hauled a reluctant orange cat in to view of the camera. "Say hi. Do you have a cat?"

I did not. I did however have two miniature hamsters who were naturals on camera. After a few minutes, I had one of the hamsters inquire about her upcoming procedure.

"We can talk about that, but first let's go to my room," she said. "I will show you my horses."

Down I went in a nauseating tumble of camera angles as she dropped the iPad into her doll stroller. I saw her mother go by, smiling, as I was pushed through the living room.

The remainder of our session involved a tour of her room, bookshelf, stuffed animals, and special jewelry box. Interspersed into this I purposefully opened questions and gave simple information about her procedure, and she listened as she played and even rehearsed breathing in an anesthesia mask before helping all her stuffed animals “fall asleep” in a line on the floor. She was able to face it from the comfort of her own space, and I watched in humble surprise as many of the foundations of my work (therapeutic play, trust, relationship-building, coping rehearsal) became possible even over a Zoom screen. According to this girl’s mother, she continued this play narrative for several days after the session and ended up coping very well with her procedure.

Since that day I have had many sessions with pediatric patients via Zoom. As with in-person interactions, not all of them have been successful in connecting with the child. However, these experiences have allowed me to develop a wide range of telehealth creativity that I did not previously have, some of which is made even more possible by the particular dimensions of a Zoom screen. Puppets and animated stuffed animals, for example, have been foundational in my work throughout my career but have been especially useful via Zoom as they are able to enter and exit the screen, peek around corners, “surprise” me, and talk directly to the child while I am offscreen. One session involved a COVID-positive patient who was in her room alone and who was too shy to talk to me, but who was able to make Play-doh creations with a particularly gentle-looking duck puppet that I was controlling from just out of view. As rapport was developed, the duck began to get sillier and accidentally “drop” the Play-doh with an exaggerated response, which would make the girl giggle. Eventually we were playing “catch” with balls of Play-doh that we could toss at the screen and then pretend to catch on the other end, playing in tandem despite being many miles away. This certainly would not have been possible in person since this girl was on isolation.

Other activities I have done via Zoom with patients have involved guessing games, drawing, virtual sand play, and even virtual gardening. Zoom has also expanded my ability to work with siblings in a manner that far exceeds my pre-Covid work. Where I previously might see a sibling once or twice if they came along to an appointment or in emergent situations, I can now meet with them privately on their own schedule and in their own space. I have become so grateful for this opportunity and am just beginning to explore its potential impacts.

To be clear, I still prefer in-person interaction and probably always will. I’m looking forward to a time when most of my work is in-person and when freely sharing materials and even group play is acceptable again. However, I have also come to understand and appreciate telehealth as a means of connection during a time when it would otherwise be impossible, and for the particular advantages of this medium. Zoom still doesn’t quite feel automatic to me and I am still genuinely shocked each time it successfully connects, but I also look forward to my telehealth sessions, find professional growth in thinking up Zoom-friendly activities, and find deep appreciation for the fact that the kids are always better at it than I am.

Additionally, I’ve come to find that authentic conversations, connections, and relationship building is possible on Zoom, and that, despite the obvious distance of being in separate places,

Zoom allows for a kind of intimacy that I did not expect. It allows me to truly meet a family where they are at, in their own space, and in a manner that makes me the grateful visitor to that space. It also levels medical hierarchies and encourages a “we’re in this thing together” mentality, be that the pandemic at large (“Hey, we’re both in our living room!”) or our corresponding inability to fully master the mute button. This ongoing experience has solidified in me a comforting hope: Even in the face of immense barriers and in the worst of times, humans simply can’t help but find ways to reach out to one another. We may still need to be apart for now, but it makes me feel like we are and will be, both literally and figuratively, there with each other on the other side.

-###-

A PERSONAL REFLECTION ON 30 YEARS OF GLIMMERS OF HOPE

Stacy F. Orloff, Ed.D., LCSW, ACHP-SW

Vice President, Innovation and Community Health

Empath Health

Clearwater, FL

stacyorloff@empathhealth.org

*"It's always something, to know you've done the most you could.
But, don't leave off hoping, or it's of no use doing anything. Hope, hope to the last!"
Charles Dickens*

I've been directly involved in pediatric hospice and palliative care work for over 30 years. I began my work as a pediatric social worker at a very large hospice whose children's program was mostly focused on healthy children of adult hospice patients. We did care for a few ill children, and I was grateful to be given the chance to work directly with them. I clearly remember the first family that taught me about hope. They had three sons, two with hemophilia, one of whom had contracted HIV through a blood transfusion. Where I saw a very young pre-teen with a fatal disease (this was in the early 1990's and HIV was mostly a fatal disease then), he saw himself as a pre-teen with a lot to conquer. This young man taught me about life. He taught me to see a beautiful wildflower in a sea of weeds. He taught me about having fun, even if that meant playing basketball with him while wearing a dress and heels. He taught me to face my own fears when he placed a very large iguana lizard on my arm! He taught me about living each day to its fullest, not knowing how many days there were. And, when his days were diminishing, he, as a young adult, taught me how to say goodbye with grace on the telephone. This young man lived every day full of hope and fun.

Each child I met early in my hospice career taught me something about hope. Every life mattered and I learned there is much to be hopeful for and about. As I was promoted into different leadership positions over the last 30 years, I wondered if I would lose that sense of hope and wonderment. No longer working directly with our pediatric patients and their families, would I lose sight of moments in time which sustained hope to so many? Thankfully I found out the answer to that question was a resounding no.

Hope to increase access to care is what propels me to design new programs and services for ill children and their families in our service area. Advocating in my state and nationally for those who are often not heard and frequently overlooked gives me hope that when a family asks for a service we can say, "Yes, we provide that type of care." Developing deeper collaborative relationships with other providers so that we decrease the silos that are found in our healthcare system gives me hope that navigating through the healthcare system becomes easier and more children and families are more quickly connected to care providers. Seeing ourselves less as competitors and more as partners in service to others gives me hope when

convening with other pediatric hospice and palliative care providers. Talking with state and national payers and hearing them express understanding about the barriers to care gives me hope. I have even greater hope when these payers join with providers to find ways to reduce barriers. Training and mentoring staff who want to learn best practices in providing care to ill children and their families gives me hope.

In my mind's eye, I see all my lessons of hope arranged in a beautiful sparkling vase on my desk. Much like a beautiful floral arrangement, the beautiful lights of collected hope shine brightly and continue guiding me today. My greatest wish is that I continue collecting these glimmers of hope and that my vase gets fuller and fuller.

-###-

GLIMMERS OF HOPE: WHAT THE COVID-19 PANDEMIC HAS TAUGHT PEDIATRIC PALLIATIVE CARE

Danielle Faye Jonas, MSW, LCSW

PhD Candidate
Silver School of Social Work
New York University
dfj215@nyu.edu

Lauren Cramer, MSW, LICSW,

Clinical Social Worker
Pediatric Advanced Care Team
Boston Children's Hospital and Dana-Farber Cancer Institute
CramerLaurenM@gmail.com

Jennifer Greenman, MSW, LCSW

Clinical Social Worker
Division of Comfort and Palliative Care
Children's Hospital Los Angeles
jennifer.a.greenman@gmail.com

Rachel Rusch, MSW, LCSW, MA,

Clinical Social Worker
Division of Comfort and Palliative Care
Children's Hospital Los Angeles
ruschrachel@gmail.com

Caitlin Scanlon, MSW, LCSW

Clinical Social Worker
Pediatric Palliative Care Team
Riley Hospital for Children
Indiana University Health
caitlinscanlon725@gmail.com

The COVID-19 pandemic seems to have shifted the world on its axis and has led to many changes in the way health care and specifically pediatric palliative care (PPC) is delivered to patients and families. While this period has been a trying time for health care providers and patients and families alike, many “glimmers of light” have emerged as the field of PPC shifted practice to optimize patient care. This article will elucidate some of the lessons learned by PPC social workers throughout the pandemic with regards to confronting systemic racism, building community, adjusting to telemedicine, and modifying bereavement practices to improve access, and how these lessons can inform practice moving forward.

Call to Action to Address Systemic Racism

A light that had glimmered long before COVID-19 was one that was guiding the field of PPC toward the need for great change. Systems of health care in the United States have long been unsuccessful in truly treating and caring for the complete community. The pandemic shone an even greater spotlight on this need for change—and while there are immense efforts that lie ahead, this bright and necessary spotlight now guides the field of medicine toward creating new systems for future generations to come that are long overdue. PPC is poised to lead these efforts, given the field's expertise in advanced communication and assessment of individual culture and perspective.

The pandemic threw into even greater relief the inequities, marginalization, and bias that continue to be pervasive in American culture and deeply embedded in our medical systems. The year 2020 brought about deepened initiatives, education, and efforts for systemic change toward representation within hospitals and health care institutions across the country, especially within PPC. The pervasive and insidious ways in which bias and marginalization impact the delivery, educational pipeline, and provision of health care can no longer be ignored. PPC can continue to lead such efforts, offering attunement to the experience of those served toward bettering greater systems of care. This difficult and challenging time has pushed the field forward into a necessary reckoning and the creation of new systems that are long overdue.

The strain on health care systems and their human workforce have continued into 2021. Many feel that the glimmers of light toward a return to “normal times” remain elusive. Alongside this is the potential shattering of notions of what it means to sustain oneself in a career in PPC. As the realities of the pandemic in the United States continue, so does a deepening call for a prioritization of sustainability and organizational actions in support of the wellbeing of clinicians. Intuitions are recognizing that supporting a thriving workforce that can maintain in the face of great difficulty requires acts of meaningful change and multifaceted organizational efforts. The humanity of health care is being reconsidered, as well as hope that the light of reexamination will usher in new models of sustainable health care in the time to come.

Building Community

Health care workers experienced the rapid adjustment and shift to increased telehealth and virtual formats for gatherings due to physical distancing guidelines amidst the emerging pandemic. The transition demonstrated that pediatric palliative care social workers, alongside our fellow interdisciplinary clinicians, could creatively meet the evolving needs of our patients from a distance. This transition also far exceeded expectations, having increased access to both national and local opportunities for professional development as well as community building.

The Social Work Hospice and Palliative Care Network (SWHPN) adapted its yearly national conference to a virtual summit format. These interactive half-day summits brought together psychosocial clinicians from a variety of settings, including their homes or workplaces across

the country. The summits provided opportunities to present and learn about evolving research, innovative practices, and case narratives focused on diverse areas within the field of hospice and palliative care. They also provided a source of connection and support when many providers were feeling isolated and disconnected from community members.

Numerous hospital institutions, including PPC teams, also began offering virtual grand rounds. These virtual forums expanded access for interdisciplinary audiences to learn from leaders within the field. This format also further enabled family-centered rounds, allowing parents and caregivers a platform to share their experience with medical staff and community members from a distance.

While different than in-person encounters, specialized interventions utilizing virtual formats fostered connectedness. A group of PPC social workers, mostly graduates of the PACT Social Work Fellowship Program through Harvard Medical School, Boston Children's Hospital, and the Dana-Farber Cancer Institute, created a weekly PACT Zoom Town Hall (Jonas et al, 2021). This weekly forum offered support, sharing, and collaboration amongst peers working across all regions of the United States and in multiple work environments, including hospitals, community settings, and academic arenas. The group provided mutual support while navigating new complexities of care for children with serious illness and their families in the setting of COVID-19 and as the pandemic resulted in hotspots across the country.

Transitioning to Telehealth

As the world of medicine was forced to simultaneously address both pandemic safety and needs of the patients and families, providers were thrust abruptly into usage of telehealth. While many providers had dabbled with telehealth, most were not accustomed to relying on this format as a primary source of patient interactions. At the start of the pandemic, administrations scrambled to determine which platforms would best meet the needs of the patients their systems serve, and clinical providers rushed to reimagine how to provide high levels of care through a screen for the foreseeable future. Utilizing telehealth for the palliative care population was especially important given the vulnerability and susceptibility to a life-threatening, novel virus.

While there was a learning curve, many providers quickly noticed a multitude of benefits that telehealth provided. Providers were often surprised to realize how at ease patients felt in their own space and how this comfortability improved rapport building. Social workers also observed this level of comfort in practice with children and adolescents and noted success with engagement using this modality (Jonas et. al, 2021). Another benefit was that families had opportunities to show providers what their homes looked like, offering additional insight into the family, fostering improved relationship building, and providing space for suggestions around managing activities of daily living.

The use of telehealth created an opportunity for families to access palliative care services more readily without necessitating an arduous trip to clinic. Many children with medical complexity

have several assistive devices and challenges with mobility, requiring additional assistance to come to appointments. Some families travel hours to come to appointments. With the use of telehealth, families were able to arrange appointments that met their scheduling needs and more frequently, multiple parents or caregivers were able to be present as barriers were addressed.

While telehealth is not without faults, it revealed many opportunities for connections and increased access to palliative care services during a time of significant isolation.

Modifying Bereavement Support

During the COVID-19 pandemic, PPC social workers found themselves faced with the challenge of adapting bereavement programming to virtual formats. Bereavement support following the death of a child is a central element of pediatric palliative care social work practice, and a crucial service for caregivers and family members of all ages. Though PPC social workers worried about the effectivity of virtual group support, adult and sibling group participant and facilitator feedback was overwhelmingly positive following the first virtual HOPE Group bereavement groups. The HOPE Group model was created and established by Marsha Joselow at Boston Children's Hospital/Dana Farber Cancer Institute and has been adopted by various other programs nationwide.

Upon hearing about Virtual HOPE Group development, parents/caregivers expressed enthusiasm for the opportunity to participate, and deep appreciation for the offering (Jonas et al., 2021). They shared that while connecting with safety guidelines around COVID-19, they also experienced isolation and disconnect from previously identified supports. Participants noted that the virtual intervention increased accessibility and that it allowed for participant connection in new and innovative ways. Parents/caregivers shared photographs, meaningful memorials, and spaces linked to their deceased child. They described feeling comfort in joining from chosen locations, and facilitators noted that this may have allowed for deeper engagement and exploration into challenging topics.

Virtual Sibling HOPE Group participants described forming meaningful connections with each other through the virtual platform, noted decreased feelings of isolation, increased confidence, comfort in communication with loved ones, and enhancement of coping mechanisms (Jonas et al., 2021). Siblings also connected with the ability to bring meaningful context from home into the group, shared feelings of comfort associated with participation from their chosen spaces, and demonstrated successful group formation through the virtual modality.

The newness of virtual group interventions provided HOPE Group facilitators with the opportunity to create novel programming with potential to inform virtual support practice long after COVID-19. Parent/caregiver group facilitators developed a document guiding participants around navigation of the virtual platform and establishing a healing environment. Sibling group facilitators created boxes mailed to siblings containing personalized letters, supplies, and written instructions for interventions that coincided with planned groups to preserve

programming that allowed for expressive arts, therapeutic play, and bibliotherapeutic interventions in virtual facilitation.

Participants in both group types endorsed the virtual group format as well as the success of interventions. PPC social workers have reported plans to continue virtual group offerings alongside future in-person support.

Conclusion

While the COVID-19 pandemic continues to be an incredibly challenging time to work in health care, this period has afforded the field of PPC the opportunity to consider ways to improve care and access to care for patients and families. These glimmers of light remind the field that by continuing to confront systemic racism, offering improvements for access to care, maximizing community building and professional development, and growing bereavement resources, the field can continue to grow amidst trials and tribulations.

Reference

Jonas, D. F., Drouin, K., Greenman, J., Klein, V., Scanlon, C., Frechette, E., ... & Purol, N. (2021). The Long Shadow: Collateral Impact and Finding Resilience Amidst a Global Pandemic *Pediatric Palliative Care Social Work During COVID-19. Journal of Social Work in End-of-Life & Palliative Care*, 17:2-3, 218-236, DOI: [10.1080/15524256.2021.1894312](https://doi.org/10.1080/15524256.2021.1894312)

-###-

“HOPE GETS US THROUGH LITERALLY EVERY DAY”: STRATEGIES FOR KEEPING PARENTAL HOPE POSSIBLE IN PEDIATRIC PALLIATIVE CARE

Jill M. G. Bally, RN, PhD

Associate Professor

College of Nursing, University of Saskatchewan

Saskatoon, Saskatchewan, CA

jill.bally@usask.ca

and

Meridith Burles, PhD

Research Associate

College of Nursing, University of Saskatchewan

and Sessional Lecturer

Department of Sociology, University of Saskatchewan

Saskatoon, Saskatchewan, CA

meridith.burles@usask.ca

Historically, hope has been identified as an important concept in many disciplines including sociology, psychology, theology, medicine, and nursing (Dufault & Martocchio, 1985; Duggleby et al., 2010; Hearth, 1993; Jevne, 2005; Snyder, 2000). In healthcare, hope science has helped to inform the way in which providers interact with those for whom they care in order to provide holistic and comprehensive care. Duggleby et al. (2010) describe hope as being of widespread importance independent of age, relationship, or setting. They define hope as “transitional dynamic possibilities within uncertainty” (Duggleby et al, 2010, p. 148). Specifically, amidst fluctuating emotions and illness-related uncertainty, parental caregivers describe hope as an important coping resource in their daily lives with children who have medical complexity related to life limiting (LLI) and life-threatening illnesses (LTI) (Bally et al., 2021). For example, parents of children in treatment for cancer have suggested that ‘Keeping Hope Possible’ (KHP) is an important aspect of their everyday lives, helping to sustain their wellness and caregiving activities (Bally et al., 2014). Keeping hope possible involves four important processes including accepting the reality of their child’s illness, establishing control in some aspects of daily life, restructuring hope as needed across the illness trajectory, and maintaining positive thinking. These four processes facilitate KHP, and constitute the framework for the KHP Toolkit, a supportive healthcare resource. The KHP Toolkit is a self-administered tool that offers parents support with the difficult practical and emotional work involved in caring for their child who has a LLI or LTI.

An important component of the coping process involves parental management of difficult emotions and worries about negative outcomes for the child and other family members.

Accordingly, health care providers can use the KHP Toolkit to implement strategies to support families in keeping their hope possible over the course of the illness trajectory. Strategies that care providers in pediatric palliative care settings can use to support parents include mindfulness, self-care and social support, celebrating milestones and creating legacies, and acquiring information.

Mindfulness

A focus on mindfulness can help to quell negativity and overwhelming feelings by bringing attention back to the present and reinstating a sense of control. Parents describe many competing feelings of anxiety, stress, uncertainty, loss of control, and fear. Therefore, paying increased attention to one's breathing or body is a simple activity that parents can engage in almost anywhere, but especially when in the hospital with their child or while waiting for medical appointments.

Other activities such as finger labyrinths, coloring, and art offer extended means for being mindful. Existing research has shown that art can offer a creative outlet for releasing emotions for children and their families (Derman & Deatruck, 2016), and parents have expressed their appreciation of having a relaxing way to pass time and/or an activity to do with their child (Bally et al., 2021). Similarly, focused and/or free journaling may support parents in freeing their minds of those feelings and thoughts that can accumulate and weigh heavily. For focused writing, parents can be provided with a few prompts to guide this process such as: take some time to write about your thoughts today; allow yourself to feel your emotions and write about them here; and, what does hope mean to you today and how can you achieve this? (Bally et al., 2020). Parents can also be supported in learning how to journal freely, with no prompts but in a way that is flexible and self-guided to encourage the release of emotions and feelings. While difficult emotions can be challenging to talk about, some parents appreciate the chance to think about and write them down as a means to acknowledge and create emotional distance from them (Bally et al., 2021; Burles et al., submitted a). Overall, by supporting parents in reducing the overwhelming feelings that they may be experiencing, specialists in pediatric palliative care can help parents to keep their hope possible, which supports the necessary work of experiencing all emotions and feelings but returning to a more positive and functional mindset.

Self-Care and Social Support

Another important area in which family caregivers can be offered practical support is with respect to self-care and access to social supports. Caregiving is associated with self-care deficits (Koch et al., 2021); despite that, small steps to promote caregiver well-being are essential to sustaining caregiving for the child and family over time. As well, self-care is a component of post-traumatic growth, which is associated with personal strength and development, connection to others, advocacy, and identification of one's own needs and steps to meet them (Cadell et al., 2012). While self-care activities such as exercise, diet, time to self, nurturing relationships, professional support/counseling, identification of concerns, and sleep quality have been highlighted as modifiable factors that can be addressed through support

interventions (Cadell et al., 2012), self-care can take various forms according to family caregivers' preferences and needs. For instance, small efforts to support parents' time for their own well-being can involve short breaks to attend to themselves, including time to comb their hair, shower, drink a cup of tea, or enjoy time outside of the care setting with a friend or family member. While some parents might perceive self-care as self-indulgent given their family circumstances, bringing about awareness of their daily needs can promote identification of strategies to meet these needs, which can have benefits to well-being and self-efficacy amidst challenges.

Although some family caregivers will downplay their own needs and prioritize others, the availability of social support remains important. That is, the perception that supports can be accessed if necessary is beneficial and can minimize the possibility of role overload, which is commonly experienced by this population (Koch et al., 2021). Therefore, sharing information with families about formal supports is crucial, even if they are resistant to seeking outside assistance or respite. As well, encouragement to document formal and informal sources of support can ensure that family caregivers know who to turn to if they feel overwhelmed (Smith et al., 2018). Thus, perceived access to supports can keep hope possible via recognition that family caregivers are not alone in navigating their child's illness (Bally et al., 2020).

Celebrating Milestones and Creating Legacies

Another means for keeping hope possible throughout a child's LTI/LLI trajectory can emerge from recognition of important events and time spent doing enjoyable activities as a family. Uncertainty can pose immense challenges for families, but acknowledgement of minor achievements to significant milestones can offer a chance to reflect on positive aspects of experience and help parents and families to keep hope possible (Bally et al., 2021). As well, attention has been drawn to the importance of creating family memories and traditions amidst the challenges and unpredictability of their child's illness. For example, establishing a weekly family meal night with all members of the family or getting a favorite food or treat to celebrate following a treatment session or medical procedure are among various activities reported by parents (Bally et al., 2021; Burles et al., submitted a). As well, finding ways to create a legacy for the child can allow families to identify some form of meaning in their experiences (Burles & Bally, submitted b). Creating family stories, such as through art making or digital storytelling, is a way for families to spend time together, communicate their feelings, and generate a meaningful product or memory (Driessnack, 2017; Laing et al., 2017). Awareness and fundraising, advocacy work, and commemoration of other children and families who have gone through illness-related challenges have also been noted as strategies for creating a legacy out of the adversity that families face (Burles & Bally, submitted b; Cadell et al., 2012).

Acquiring Information

Finally, the loss of control that is introduced by a child's diagnosis with an LTI/LLI can disrupt all aspects of daily life and well-being (Bally et al., 2021). Feelings of powerlessness and senselessness can diminish hope in family caregivers. Thus, it is essential to find strategies for

parents to re-establish control in some aspects of their lives. Ensuring that the basic needs of the family are met is important, as is gaining a clear understanding of the child's condition through acquisition of meaningful information (Bally et al., 2014). Accordingly, healthcare providers in pediatric palliative care can work with family caregivers to ensure their understanding of care practices and involvement in care provision, which can foster a greater sense of control within their child's illness experience along with self-reliance and empowerment. As well, finding opportunities for active involvement in care of the child can benefit self-efficacy, which correlates to hope in family caregivers (Bally et al., 2021; Burles et al., submitted a).

Conclusion

While "hope" is often used in a conversational manner, parents whose children are in treatment for a LLI or LTI can benefit from keeping hope possible in terms of their overall health and caregiving activities. As such, it is important for pediatric palliative care providers to recognize the critical nature of hope and include assessment and strategies to help parents keep hope possible. Acknowledging that parents' hope is dynamic and a resourceful response to often traumatic and challenging circumstances will provide a foundation from which to develop supportive discussions. In addition, the KHP Toolkit can be used to help parents engage in hopeful activities including mindfulness, self-care, garnering social support, celebrating milestones, creating legacies, and acquiring information.

References

- Bally, J. M., Burles, M., Spurr, S., Holtslander, L., Hodgson-Viden, H., Sinha, R., & Zimmer, M. (2021). Keeping Hope Possible Toolkit: The development and evaluation of a psychosocial intervention for parents of infants, children, and adolescents with life limiting and life threatening illnesses. *Children*, 8(3), 218. <https://doi.org/10.3390/children8030218>
- Bally, J. M., Burles, M., Smith, N. R., Holtslander, L., Mpofu, C., Hodgson-Viden, H., & Zimmer, M. (2020). Exploring opportunities for holistic family care of parental caregivers of children with life-threatening or life-limiting illnesses. *Qualitative Social Work*, 20(5) 1356–1373. <http://doi.org/10.1177/1473325020967739>
- Bally, J. M., Duggleby, W., Holtslander, L., Mpofu, C., Spurr, S., Thomas, R., & Wright, K. (2014). Keeping hope possible: A grounded theory study of the hope experience of parental caregivers who have children in treatment for cancer. *Cancer Nursing*, 37(5), 363-372. doi: 10.1097/NCC.0b013e3182a453aa
- Burles, M., Bally, J.M.G, Holtslander, H, Hodgson-Viden, H., Zimmer, M. (submitted a). Supporting family caregivers of seriously ill children: Findings from a mixed methods evaluation of a theory-based hope intervention.
- Burles, M., Bally, J.M.G. (submitted b). "The Chip in a Perfect Piece of Pottery": Parental narratives of the idealized child, faith, and failure when a child has cancer.
- Cadell, S., Kennedy, K., & Hemsworth, D. (2012). Informing social work practice through research with parent caregivers of a child with a life-limiting illness. *Journal of Social Work in End-of-life & Palliative Care*, 8(4), 356-381. doi: 10.1080/15524256.2012.732021

- Derman, Y. E., & Deatrick, J. A. (2016). Promotion of well-being during treatment for childhood cancer: A literature review of art interventions as a coping strategy. *Cancer Nursing, 39*(6), E1-E16. doi: 10.1097/NCC.0000000000000318
- Driessnack, M. (2017). "Who are you from?": The importance of family stories. *Journal of Family Nursing, 23*(4), 434-449. <https://doi.org/10.1177/1074840717735510>
- Duffault, K., & Martocchio, B. C. (1985). Hope: Its spheres and dimensions. *Nursing Clinics of North America, 20*(2), 379-391.
- Dugleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C., & Williams, A. (2010). Metasynthesis of the hope experience of family caregivers of persons with chronic illness. *Qualitative Health Research, 20*(2), 148-158. doi: 10.1177/1049732309358329
- Herth, K. A. (1993). Hope in family caregivers of terminally ill people. *Journal of Advanced Nursing, 18*(4), 538-548.
- Jevne, R. (2005). Hope: The simplicity and complexity. In J. Eliot (Ed.), *Interdisciplinary perspectives on hope* (pp. 259-291). New York: Nova Science.
- Koch, A., Kozhumam, A. S., Seeler, E., Docherty, S. L., & Brandon, D. (2021). Multiple roles of parental caregivers of children with complex life-threatening conditions: A qualitative descriptive analysis. *Journal of Pediatric Nursing, 61*, 67-74. <https://doi.org/10.1016/j.pedn.2021.03.017>
- Laing, C. M., Moules, N. J., Estefan, A., & Lang, M. (2017). Stories that heal: Understanding the effects of creating digital stories with pediatric and adolescent/young adult oncology patients. *Journal of Pediatric Oncology Nursing, 34*(4), 272-282.
- Smith, N. R., Bally, J. M., Holtslander, L., Peacock, S., Spurr, S., Hodgson-Viden, H., ... & Zimmer, M. (2018). Supporting parental caregivers of children living with life-threatening or life-limiting illnesses: A Delphi study. *Journal for Specialists in Pediatric Nursing, 23*(4), e12226. DOI: 10.1111/jspn.12226
- Snyder, C. R. (2000). Genesis: Birth and growth of hope. In C. R. Snyder (Ed.), *Handbook of hope: Theory, measures, and applications* (pp. 25). San Diego, CA: Academic Press.

-###-

FINDING HOPES WHEN A CHILD DIES: HOW CAN THE MEDICAL TEAM REFRAME THE ISSUE?

Suzanne S. Toce, MD
Retired Neonatologist
Gundersen Health System
LaCrosse, WI
tocess@gmail.com

As a neonatologist, this is an intensely personal topic. When I started in my career in the late 70's, 6-12 of the newborns under my care died each month. Admittedly, it is far better now, but death of our child patients, especially those of pediatric palliative care providers, is fairly common. How can we see glimmers of hopes? How can we see the hopes in the care that we provide to the child and family? How can we experience these hopes and avoid continuing futile treatments that likely prolong suffering but allow the providers to feel as though they are doing "everything that they can"? We have to reframe our concepts of hope.

Consider this possible case: Dr. K. is a compassionate pediatric cardiologist at a children's hospital. He has cared for baby Juan, who has Down Syndrome and complex congenital heart disease, since shortly after birth. Juan has been in the NICU since birth, most of the time on the ventilator. He has developed pulmonary hypertension that is now irreversible and likely fatal. Parents visit frequently and understand his precarious situation and the need for frequent pain and sedative medications. While Dr. K. is supportive of the parents' desire to continue intensive treatment, he feels that he is a failure as he fears that Juan will die regardless of optimal treatment.

We need to reframe our concept of hope. When hope for cure or a prolonged life is no longer realistic, what are the hopes that are possible? Can we as providers help the parents and other caregivers conceive of smaller, more realistic hopes? What might these hopes be in Juan's case?

- Parents hope that:
 - They can hold Juan more frequently and spend more time with him
 - Their religious and spiritual beliefs will be supported
 - He can be baptized surrounded by his extended family
 - His siblings and extended family can visit
 - He is free of pain and distressing symptoms
 - They can continue to feel supported by the healthcare team in achieving their goals with Juan
 - They can feel certain that they have tried all treatments likely to help Juan
 - They have mementos of his life
 - They will be present when he dies
 - That his death will be peaceful

- They can be rested
 - Family life will return to normal
- Providers can hope that:
 - They feel confident that they have done everything that might be helpful to Juan and his parents
 - Parents feel informed and supported in their goal selection and treatment decisions
 - They have supported the right treatment decisions to minimize Juan's suffering

We as providers need to disentangle the concept of hope from that of a positive outcome or prolonged survival. This misunderstanding about the incompatibility of hope and realistic prognosis is complicated by the concept that there is only one hope (i.e., prolonged life) when there are, in reality, multiple possible hopes. Hopes can remain even if death is likely. The providers and the parents can simultaneously hope for the best and plan for the worst.

As a neonatologist, I could find glimmers of hope as I held the hand of one of my newborn patients as the parents held their baby and the beep of the EKG monitor slowed. The baby was at peace. The parents were at peace. I was at peace.

-###-

FOUR EXAMPLES OF KEEPING HOPE AS A PRIORITY

Jennifer Mangers, MHA, MS, CCLS

Pediatric Team Manager

Child Life Specialist

Barrington, IL

JMangers@journeycare.org

Contributors: Jennifer Leahy, LCSW; Jessica Harris, RN; & Megan Sizemore, Chaplain

Throughout the last 18 months, we saw many changes that have impacted the patients and their families in our Pediatric Hospice & Palliative Care Program. However, one consistency we found was that patients, their families, and our staff kept hope a priority whenever possible. It was uplifting and inspiring to see families find ways to continue making meaningful memories. We always encourage our families to keep hope in their minds, but what we found so powerful was that one staff member or volunteer, one small task, or one verbalized wish could bring so much hope to so many people. Here are just a few of our stories of how our patients and families kept hope in the forefront of their minds.

On Memorial Day weekend, many families and friends gathered in the back yard of a 16-year-old pediatric patient. Each attendee had a costume or face paint to celebrate the patient's favorite things. This gathering was a celebration of life as well as a declaration of her mom's dedication. Before eating tons of food and having a reptile show in the yard, which is a favorite of the patient, a handfasting ceremony was provided by our chaplain. This patient and those who care for her daily tied a knot together connecting them as a symbol of their love and care for each other. This was a longstanding wish that the mother had wanted and was able to make possible even during the limitations of COVID-19.

We had a 20-year-old pediatric patient with cancer in his brain and spine. Despite several rounds of chemo and radiation, the cancer continued to grow, and rapidly. There were no longer any treatment options for him that would slow the progression. He is from the Philippines and his mom was still there. She was unable to get to his U.S. home to see him, so his wish was to go home to the Philippines to spend rest of his time left with her and the rest of his family. Our team quickly worked on getting all necessary components in place including transportation, lodging, COVID testing, and shipment of supplies and medications. We had four weeks to get all this done and one week before he was to leave, he got a fever, and his kidneys were failing. He was admitted to hospital. With a strong collaboration between hospice and hospital, we were able to get him stable enough to fly home. We said our goodbyes and he went right from the hospital to the airport. Dad sent pics of their travel and when he was back home with his mom. Wish comes true!

Erik is a 21-year-old young man diagnosed with Friedreich's Ataxia. He was admitted to our program in June of 2020. At the time of referral there were concerns about his changes in mood due to his worsening condition. He had shared with his hospital-based palliative care (PC) team that "his joy comes from his education" and that he loves "math and science and physical education," but there was an awareness that his worsening condition may prevent him from fully exploring these passions of his. When our team met with Erik, he told us that his goal was to be a bioengineer so that he can "help others" who have neuromuscular diseases like him. He was feeling worried, however, as due to COVID restrictions he was not able to go to school to learn more about this field and explore what college programs he would need to take to get a degree in this field. We reached out to our volunteer program and volunteer students who were studying the field of bioengineering were connected with Erik. These students regularly have video sessions with Erik to talk about the field, classwork, and explore Erik's perspectives and skill set. Erik also began sessions with our Chaplain who reads books to Erik about others like him who are struggling with the limitations of their bodies while having limitless goals for learning how to help themselves and others. The family reports that the supports provided by our team have provided hope for Erik to allow him to reach his fullest potential and his personal goal to help others.

We had an 8-year-old boy with ALL on our service. Chemo and stem cell transplant were not effective. Along with this cancer diagnosis, he had many unexpected issues arise. He fought daily to still be a kid and enjoy life the best he could, but eventually his body was too weak to keep going. Mom brought him home to be on hospice and spend time with his brothers and family. Mom was pregnant and unexpectedly went into early labor and had a C-section. On the same day as the delivery, a nurse visited the home and found the patient was actively dying. Mom was devastated at not being able to be at home with her dying son. With just having a C-section we did not see that it would be possible for her to be discharged, but never doubt the will power of a mother. Mom discussed the situation with the doctors at the hospital and they agreed to discharge her that afternoon. Mom came home and the house was filled with family and friends. Mom sat at her son's bedside until he passed away two hours later.

Michelle is a 24-year-old with the diagnosis of Hallermann-Streiff Syndrome. At the time of the referral, she had recently had a central line placed for continuous TPN and medication administration—or in Michelle's terms, she got another "thing" (the pump) she had to carry around with her. Prior to this most recent hospitalization, Michelle was an active young woman who attended a day program a few days a week, volunteered at an animal shelter, and worked a part time job. Unfortunately, the changes in her medical status, concerns about COVID exposure, and this "thing" meant that these activities had to be halted. In our talks with the family and Michelle, it became rapidly apparent that losing her social networks was a significant blow to Michelle and she was showing signs of despondency and frustration due to this loss. In response, our team (APN, Chaplain, Child Life, and Social Work) reached out to our volunteer services to see if we could set up some sort of social "outing" for Michelle. We had expected to have a one-time chat or one or two volunteers doing something such as watching a movie. We were thrilled to find that numerous same-aged volunteers reached out to be a part of providing social support for Michelle. What had originally started as a singular "night out" event became

a bi-monthly social group. The family reports that these social outlets for Michelle have been crucial in helping manage the ongoing changes in her medical condition.

While these are just a few of our patients' stories, they truly highlight that hope can come in all shapes and sizes. It is a constant reminder to our Pediatric Program to continue to do the important work we do so that our patients and their families can make it possible to live their lives the best way they are able.

-###-

CAPTURING GLIMMERS OF LIGHT THROUGH PHOTOGRAPHY

Karen Henrich

Founder, Moment by Moment

KarenHenrich@pacbell.net

and

Mason Henrich

Photographer, Moment by Moment

masonhenrich@gmail.com

As photographers, we capture images of children through our camera lenses. When you look at the photos, you see children through our eyes. You see freckles, bruises, giggles, and tears, but through the eyes of the children themselves, we see what is truly important. To see the world through the eyes of a child is to see a world filled with joy, excitement, love, purity, peace, curiosity, and, most importantly, wonder, no matter if they are healthy or potentially life-limited. Fifteen years ago, the non-profit Moment by Moment was established so that, through our lenses, we can capture the determination illuminated by children that have a potential life-limiting or chronically life-impacting disease or disorder. With a cadre of professional photographers in California, we have captured precious images of thousands of children and their families in both the children's hospital and pediatric hospice settings, always at no charge to the family. Through these poignant images, it is evident that the spirit of a child does not hide in their illness. Instead, they radiate hope, courage, and an unbreakable connection with their families. We capture those glimmers of light that will provide indelible memories to share with others.

"Why take portraits for a family during such a difficult time when their child is ill?" This is a pervasive question that inevitably arises when we explain our mission statement to someone. The simple answer: more than ever, families in these situations want to document and celebrate what they have this day, this moment. Perhaps it is more than that, though. Usually, we think of photography as an opportunity to capture a memorable moment in time without giving thought to its potential healing power or therapeutic dimension. However, just as photographs immortalize a moment, they also express and evoke a sentiment unique to each individual who views them. Therefore, capturing a moment of beauty allows the viewer to pause for a few seconds, feel life run through the image, feel connected, and remember that in living life, we are only secured this moment. When viewed in this light, we can begin to comprehend the enormous healing power of photographs. In fact, Photo Therapy techniques are therapy practices that use people's personal images taken by others (and the feelings and memories those photos evoke) as catalysts to deepen insight and enhance communication during sessions in ways not possible using words alone. In the setting of our unique mission, we

witness the capacity of photographs to act as expressions of love, objects of hope, and tools in the process of grief.

It is our blessing to work with these families, and for each one, through images, we paint a visual story. Some stories continue on year to year, while other stories cut short by the ravages of cruel diseases are still so vibrantly portrayed. For Abby, her Cheshire grin illuminated the room when, after she snuck a second lollypop, she ran to her mom, wrapped her arms around her mother's neck, and offered her a lick. These images told the story of her playful personality and the adoration she had for her mother. For Caitlyn, in her prom dress, it was the first time she had ever worn a formal dress, and she sparkled in it as much as the beads on the dress sparkled when the sun hit them. These images provided a vision for her parents of her dressed fancy as she would be on the wedding day that sorrowfully she would not ever be able to experience. For Arturo, standing on his tippy toes to achieve his dad's height, looking dapper in his classic three-piece suit. One could already see the striking stature of determination he would have exhibited as a grown man.

Natalie was turning eight years old the weekend that we met her family in Napa to capture her images. Exuberantly, this little girl popped out of her car and rhythmically skipped towards us, her smile sure to ignite the mustard growing in the nearby field where we planned to shoot. The mustard bloom cast a flax-colored hue in the setting sun. "Natalie's hair was about that color," her mother expressed as she reflected upon the little girl now shepherding her toddling brother from the car and towards us. Her eyes were reflective of a mixture of sorrow and reminiscence, and her head was shaven in glorious solidarity with her daughter. "The whole family chose to shave their heads when Natalie began to lose her hair," she explained. At this point, Natalie and Owen had gotten close enough to hear our conversation. "We even shaved our dog's hair off," Natalie shared with an engaging grin. Following Natalie's lead, off to the field we skipped. Through the camera, we caught a spirited little girl who would not let leukemia dull her curiosity. Natalie, Owen, and we played hide and seek in the vines and chased a few feral cats (although we believe it would have been easier to catch the cats than those two!). All the while, the wind teased the air, gently blowing my unbanded hair. Observing the fussing with my hair, Natalie said, "you should shave your head, and your hair won't be in your eyes anymore." We were struck by the simplicity and the classic logic of her statement. "That is true, and hey Natalie, where is your dog?" we asked. We knew a golden retriever would not be able to resist a car ride and a chance to lead the energetic run with his boy and girl. "Well," she began, again very matter of factly, "do you remember when I told you that we shaved Charlie too? He looks way too ugly to be in our pictures. He looks like a huge rat, and I don't want him to ruin our pretty pictures." "Oh, we can understand," I replied through a giggle. It was endearing that Natalie focused on what is truly beautiful, a family that together was doing all that they could to establish normalcy for her, a little girl going through a tough battle with grace and dignity.

As photographers, we reflect on how blessed we are after each shoot that today we do not have to comfort a child fighting illness. Today, we do not have to meet with a team of specialists who, no matter how much training they have, still cannot tell us for certain that our

child will be “fine.” Today, we do not have to spend the day with our child in the confines of hospital walls, not able to play with them in the park breathing in the cool, crisp air of early fall. Today, we are grateful that we can afford time for the luxuries of a workout and coffee with a friend without feeling that we should instead be at our child’s bedside in the confines of our home. Today, just for this moment, we are grateful to be on the outside, as photographers, capturing these precious moments of a family that will translate into irreplaceable memories of a child who will make an indelible mark on this world, no matter how long he or she is in it.









###

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.nhpco.org/pediatrics. Also, more palliative care resources are available at www.nhpco.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
- **[NHPCO's Palliative Care Resource Series](#)** includes pediatric palliative resources like:
 - *Communication Between Parents and Health Care Professionals Enhances Satisfaction Among Parents of the Children with Severe Spinal Muscular Atrophy*
 - *Consideration for Complex Pediatric Palliative Care Discharges*
 - *Songs of the Dying: The Case for Music Therapy in Pediatric Palliative and Hospice Care*
 - *Nonpharmacological Pain Management for Children*
 - *Sibling Grief*
 - *Pediatric Pain Management Strategies*
 - *Communicating with a Child Experiencing the Death of a Loved One: Developmental Considerations*

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 Resource on Medication Coverage:**

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

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

Sustainability will be the topic for our first issue in 2022. If you have any thoughts about sustainability or any other topics, contributors, or future issues, please contact Christy at christytork@gmail.com or Suzanne Toce at tocess@gmail.com.

-###-



NHPCO

National Hospice and Palliative
Care Organization

NHPCO

1731 King Street
Alexandria, VA 22314

tel. 703.837.1500 | nhpco.org