

# **PEDIATRIC HOSPICE AND PALLIATIVE CARE IN THE COMMUNITY**

ISSUE #69 | NOVEMBER 2022



## Pediatric E-Journal

**PEDIATRIC ADVISORY COUNCIL**

*Released in collaboration with the National Hospice and Palliative Care Organization*



**NHPCO**

National Hospice and Palliative  
Care Organization

# Pediatric e-Journal

## Pediatric Palliative and Hospice Care

Issue #69 | November 2022

### Issue Topic: Pediatric Hospice and Palliative Care in the Community

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Welcome to the 69th issue of our Pediatric e-Journal. In this issue, we focus on the delivery of pediatric hospice and palliative care in the community. Our goal is to explore why and how such care is or would be appropriate for delivery in the community. A very large share of pediatric hospice and palliative care has historically been delivered in hospitals, hospices, or other facilities. Is that the only option, particularly for children with medical complexity? Would community care have advantages for such children and adolescents, and for their family members? Are there also advantages for the professionals and the organizations for which they work to encourage care in the community?

Answers to these questions appear in this issue in an almost equal balance from community-based hospice or palliative care authors and from hospital-based authors. Because this is a relatively new area of care delivery, we do not expect that a single issue will cover every possible aspect of this topic, but we hope to stimulate discussion on at least some of its major dimensions—and perhaps also to bring to readers' attention some of its lesser-known aspects.

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/palliativecare/pediatrics/](http://www.nhpco.org/palliativecare/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 perinatal and neonatal hospice and palliative care, and standards for the issues in 2023. If you have any thoughts about these or any other topics, contributors, or future issues, please contact Christy Torkildson at [christy.torkildson@gcu.edu](mailto:christy.torkildson@gcu.edu) or Suzanne Toce at [tocess@gmail.com](mailto: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.

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*Melissa Hunt, PharmD, BCPPS*

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*David M. Steinhorn, MD, FAAP, Allison Kuchar, MSHCA, MBA, CHES, CEOLS, Catalina Ruiz-Mesa, MD, Tara Hoit, BA, GC-C*

Beginning with some reflections on the historical development of coalitions between children's hospitals and community organizations, this article explains how the advent of concurrent care encouraged such developments. Next, the article describes "the evolution of a contemporary, community-based, middle-to-large size pediatric program...whose goal was to create a program without walls that allowed children to move freely between home and hospital with attention to continuity and open dialog between home and in-patient settings." With graphics, a table, and references, the article concludes that, "The model creates an open dialog between care providers in the hospital and community which reduces hand-off errors and creates a transparent program based upon the unique contribution of each. Parents appreciate knowing that all members of their child's care team are talking with one another, which enhances trust and rapport. Suitable for use in many community and hospital settings, the model depends on the willingness of organizations to become full partners."

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*Kathryn Scharbach, MD, MS, and Elaine Lin, MD*

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*Megyn R Sebesta, DO, Andrea Radulovic, RN, BSN, MPH, and Savithri Nageswaran, MD, MPH*

This article offers a hospital-based perspective on transitioning children with medical complexity to hospice care. While acknowledging problems that can arise in making such transitions, based on their experiences with 60 some transitions, the authors highlight four key points on this matter: (1) hospice referrals; (2) planning for discharge; (3) caregiver preparation; and (4) post-discharge follow up. While acknowledging the collaboration needed in this complex process, the authors note that, "If hospital-based clinicians understand existing resources for CMC in their community, they can assist in a more seamless transition from hospital to hospice care." To support these transitions, in addition to their article the authors offer a two-page checklist to guide the process.

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*Justin A. Yu, MD, MS, Alison J. Martin, PhD, MA, Diana Cejas, MD, MPH, Rishi K. Agrawal, MD, Amy J. Houtrow, MD, PhD, MPH*

This article discusses "how the concept of health equity applies to the intersection of PPC and CMC care in the community, as well as barriers to and strategies for achieving health equity." The authors argue that PPC's holistic approach to the care of children with medical complexity enables clinicians to "address the bias in attitudes towards children with disabilities (i.e., ableism) that is not just pervasive in health care, but still persists even among PPC clinicians"; "advocate for care plans that prioritize outcomes which actually matter to CMC families (i.e., a family-centered approach)"; "focus on improving access to PPC services so that the benefits of PPC are available to all CMC when, where, and how they need it"; "urge leaders in our field to use their positions to advocate for policy- and system-level changes which promote CMC health equity"; and "highlight that any attempts to improve services, redesign health systems, and alter state or federal health policies will be most successful and impactful if CMC and their families are equal partners in such endeavors."

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*Mark Stockton Beveridge, Jr., MD*

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*Kim Bower, MD, FAAHPM, Debra Lotstein, MD, MPH, FAAP, FAAHPM, and Christy Torkildson, PhD, RN, PHN, FPCN*

This article describes how the Children's Hospice and Palliative Care Coalition of California recently undertook to "become an independent organization allowing the pediatric community of stakeholders to re-form a coalition to focus on the unique needs of seriously-ill children in California. This article focuses on our work since 2020 in reigniting the Children's Hospice and Palliative Care Coalition of California with the goal of increasing access to community-based needed services for all seriously ill children and their families who would benefit from the support of pediatric palliative care (PPC) services." The article concludes with a series of lessons learned that will likely be relevant to PPC coalitions in other states.

# In Memory of Liz Sumner

September 12, 1956 – June 3, 2022

By Michelle Goldbach, DNP, MHA, BSN, RN



Some of you may have known Liz Sumner through different connections, some a lot longer than I, and some had the honor to walk with her through the last months of her precious life. For me, this is my personal tribute to a person that I knew over the years and had the privilege to work with in providing care to pediatric hospice patients and families.

When I think of Liz, the words of strength, compassion, determination, humor, purpose lead by a higher power, and especially the love for her two girls, Maddie and Mary Grace, come to mind. Most of us will also say that it was her dedication in promoting and advancing Pediatric Hospice and Palliative Care that we remember the most. I first encountered Liz's influence in Pediatric Hospice when I arrived at San Diego Hospice and The Institute for Palliative Care Medicine (SDH) in 2005. Her contributions here are something for which she will most be remembered. Even though Liz had moved onto another organization sometime earlier, her legacy that she left behind was clearly visible (program materials, stories from the staff, and literature she authored) and palpable everywhere. A few months after my arrival, I was asked to oversee the Pediatric and Palliative Care Program. I had a pediatric background but was new to hospice. Fortunately, the program had a solid foundation from Liz's strong leadership that made my transformation smoother.

Over the next several years I was proud to share her stories of how the program began internally to new hires and externally at conferences, public presentations, and at the nursing schools. No one in the industry will ever forget her contribution to the development of one of the first perinatal hospice programs in the country. It began with Marcella in 1999, who was pregnant and referred to Liz by her GYN. Marcella's doctor told her that her baby would not survive the delivery and that there was nothing to be done except terminate the pregnancy. Her baby, George, was diagnosed with osteogenesis imperfecta type II. However, Marcella did not want to terminate her pregnancy and sought out Liz for support, which she provided without a second thought. Anyone who knew Liz, knew that she did not hesitate to help others in need. Shortly after her delivery, Marcella started the Comfort Cub program with the support of SDH and Liz. After SDH folded in 2013, Marcella started her own 5013C. At the time, Liz was part of the Comfort Cub Board of Directors and continued to support Marcella in providing her weighted therapeutic teddy bears to the local hospitals and hospices. In 2021, Liz became the Executive Director and remained so till her death. Even today, I continue to tell this story and how Liz impacted Marcella's life and the lives of others.

During my time at SDH (2005-2009), Liz and I would see each other at the local and state pediatric coalition meetings working together as a group to develop and promote community standards in pediatric hospice and palliative care across the state of California. It was in 2011 that I found myself working at The Elizabeth Hospice (TEH). I was excited to begin my new journey and more excited to be working with Liz herself! She was the Director of the Bereavement Program and was working with a small group to develop a Pediatric and Perinatal Hospice Program! I was very blessed to be asked to be part of this group. After many hours and overcoming several barriers, we saw our first pediatric patient in November of 2012. Although everyone was excited to see us develop this program, there was some hesitation in how we were going to be able to sustain this financially and train staff in caring for pediatric patients. In both cases, we were able to exceed expectations.

I would be remiss if I didn't mention here regarding Liz's support of not only the children but for those who worked with her. When an opportunity came up for me to work with her in the bereavement department or in clinical services, she put her mentoring hat on and reviewed each role with me including the potential for my growth in the organization as well as for me professionally. This was who Liz was—someone who thought of what was best for others. She supported my decision to go into clinical services. Luckily, I was able to continue to work with her on the Pediatric Team in developing the Pediatric Care Series for our staff, a two-day Pediatric Intensive for our initial team, education for the nursing students in the community, and presentations at several local and national conferences. I remember tireless hours working together on developing a program of excellence in our community as well as sharing our knowledge with others locally and nationally. I was so honored to see her highlighted at the National Hospice and Palliative Care Organization's annual conference speaking about her end-of-life journey with her husband, Mark, and her work with pediatric and perinatal hospice. With Liz's vision and forward thinking, she brought a new excitement and innovation for Camp Erin, in which I was lucky to participate. I will never forget the hours (and our long drives to camp together) she spent to make this a wonderful experience for the kids and their families. Running around camp to make sure things followed her leadership, we were able to bring much needed care to our children and their families. Everything went smoothly, supporting new ideas by bringing in new people, and picking up the Julian Pies for all of the volunteers! In addition, I will never forget Liz running around on a golf cart during the golf fund raiser for Camp Erin—again all for the kids! And I remember the time I was working at her desk in her office, someone came in and thought I was her! But we all know there is only one Liz Sumner. Even though that Liz and we were no longer at TEH, I am pleased to write that the program continues to grow throughout San Diego and Riverside Counties.

Shortly after Liz left TEH in 2018, we were informed of her cancer diagnosis. I was able to spend time with Liz at conferences during her remission. She was ever so vibrant, positive, energetic and well...she was Liz, and knowing her we knew that nothing got in her way of her mission or goals. Since we both went in different directions after TEH, it wasn't till the spring of 2021 that we connected by email.

Over the last several years of her life, Liz continued to provide a constant presence promoting pediatric hospice care. However, Liz's compassion extended far beyond the pediatric programs she developed, the articles, textbook contributions, and test writing. She will always be remembered for the love of Maddie and Mary Grace, her dogs, her commitment to other family members, sponsoring military at the holidays (yes, she would have them at her house), her strength during her battle with cancer, and even during her illness the love and support she would provide for others experiencing their own illnesses.

Liz, I want to thank you for all you have given us; thank you for your unwavering commitment to all who came into your life. Thank you for all of the wisdom, and knowledge you shared with me. I know that I would not be where I am in my career if I had not been you. I will forever miss your smile, laughter, compassion, mentorship, and of course your vintage clothes that you wore! I am glad we had the opportunity to spend some time to catch up at a palliative care conference during your remission and to reconnect with you in the spring of 2021, by email sharing similar experiences and our passion for pediatric hospice. Unfortunately, we were not able to meet for lunch in the fall of 2021 as planned before you became too ill, which is something I will forever regret. Thank you from the bottom of my heart. I will forever be grateful to you and it has been an honor to have known you and worked alongside you. I hope to carry your passion for pediatric patients and their families throughout my life.

In closing, I will leave you with this: Liz's personal Mission Statement (with permission of her daughters).

*I am a mother, widow, sister, orphan, nurse. Leader, cancer overcomer, Catholic, a friend, live amidst many pets and infuse celebration into ordinary moments. I see a life accepting and fulfilling the plans God has for me, being a steward of what gifts I am given, revealing His love to others through my hands, words, actions. I am committed to continual growth in prayer, learning, patience, health, discernment, leading with a servant/*



*leadership approach. Meaning comes from being a comfort to others during difficulties and sharing that dark space to being light. Through my personal and professional endeavors, I see to live a life of integrity, adhering to my values, to diminish the suffering of people of all ages experiencing serious illness, grief, loneliness, and affirm their worthiness for love, comfort, dignity, and forgiveness through my leadership roles, creating programs, plans, and implementing them to accomplish this goal. I try to bring joy, celebration, laughter, authenticity, wisdom, education, affirmation, strength, and gentleness where needed and heighten the awareness of others around me of the power of gratitude, humility, kindness, and servicing others.*

### **Liz, yes you did!**

**Postscript:** I was at the reception for Liz's funeral and heard someone talking next to me. She said her name was Marcella. I interrupted as politely as I could, trying to contain my excitement. Yes, it was the very Marcella that Liz assisted in 1999 as the second Perinatal Patient at SDH and the story I have been telling since 2005! Marcella and I remain connected and are both committed to making sure Liz's legacy lives on!

Michelle Goldbach is currently the Director of Nursing of the Helen Bernardy Center at Rady Children's Hospital in San Diego California. She is actively addressing the need for continued education and care for pediatric hospice and palliative care. [mgoldbach@rchsd.org](mailto:mgoldbach@rchsd.org)

# SEIZE

Heath Ditucci

Where do you go  
When you run away  
While mute  
On the soft sewn blanket you lay  
Misfire the mind  
My attention you draw  
Tightened up trunk  
Clenched fist like a paw  
I wish for one glimpse  
One spy  
One tone  
So i know of what you endure  
Before God brings you home  
It pains me to see you suffer so great  
A pure innocent soul  
And this is your fate  
The fate handed down  
From creator above  
That made you as such  
From supposed love  
So I've struggled in the past  
To blame and ask why  
As I received and answer  
From the one on high  
Take good care he says  
For she is like you  
A helpless babe  
Like those in the pew  
That ask God for help  
For things they can't accomplish on their own  
Like the baby that seizes  
On the soft blanket seen  
You're her father  
On you she depends  
Eating up all the love she sends  
Until I call for an angel  
To take her from her stay  
But you'll never know where she goes  
When she runs away

# Where the Cellular Won't Roam

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No parent expects to spend the first year of their child's life in the hospital, but that is exactly the challenge Ashley faced with her son. Cody was born with a chromosomal anomaly associated with congenital hypotonia, chronic respiratory failure, gastrostomy tube dependence, epilepsy, and autonomic dysfunction. Prior to discharge from his initial hospitalization, he was referred to Hands of Hope (HOH), South Carolina's only statewide palliative and hospice provider with a dedicated pediatric team. Over the next three years, the team served Ashley and Cody through moves across three counties in some of South Carolina's most rural and poorly-resourced areas. Committed to providing continuity of care, HOH supported Ashley in becoming a caregiver and advocate for her son, helping Cody reach his fourth birthday, a milestone in line with her goals.

Our team provided an additional layer of support alongside Cody's pediatrician and subspecialists with the goal of maximizing his comfort and quality of life, minimizing hospitalizations and emergency department visits, and supporting and training Ashley and her support system. Cody's two years on hospice were peppered with times when Ashley did not think he would survive, and our team was able to help Ashley navigate Cody's complex care while providing resources and assistance with informed decision making.

The interdisciplinary pediatric hospice and palliative care team collaborates to maximize face-to-face time with patients. Initially, Cody was referred to hospice, which provides services and support by pediatric-trained clinicians including scheduled visits with a medical provider, nurse case manager, social worker, chaplain, dietician, and multidisciplinary bereavement services. In addition to required services as defined by the hospice benefit, HOH supports patients and families by offering services from certified child life specialists. Child life specialists facilitate interactions that enhance positive relationships within the family and encourage therapeutic self-expression, emotional exploration, legacy building, and capturing joyful memories. Additionally, child life specialists educate parents and caregivers on child development, especially when it does not follow expected patterns, and provide education on developmentally appropriate ways to help children understand death and dying.

In South Carolina, the hospice benefit for those less than 21 years of age is often delivered alongside Concurrent Care for Children as defined by the Affordable Care Act, section 2302. In short, this allows for disease-directed or curative treatment to be delivered in tandem with the hospice benefit. The relationships with community providers, including primary care providers, subspecialists, local emergency departments and hospitals, promote a unique ability to wholly care for the child and family. These relationships also provide a robust system to support home-based palliative services including establishing goals of care and symptom management plans, providing psychosocial support, and offering unique perspectives on the limitations of home environments. All HOH providers have access to electronic health records (EHR) at the state's children's hospitals. Many of these EHRs have triggers to alert HOH staff of emergency department visits, hospital admissions and discharges, and critical lab or diagnostic results. In addition, the team has relationships with all inpatient palliative care teams in these institutions. Nurse clinical liaisons ensure smooth transitions of care, often serving as the initial face of the

program with families, reviewing goals of care, and collaborating with referral sources and inpatient teams throughout a patient's journey.

The sequelae of Cody's chromosomal anomaly coupled with Ashley's goals of care for him resulted in technology dependence. Navigating the health care system is an increasingly difficult task for all, but navigating the system with a fragile, technology-dependent child while living in a rural setting away from his medical home is even more challenging. After-hours and weekend coverage for medical guidance and skilled nursing visits are key to keeping Cody at home as much as possible, in line with Ashley's wishes. To promote patient and family-centered care, medical providers attend subspecialty appointments and perform virtual visits in time of crisis to support, reinforce, or revisit goals of care or participate in mutual formulation of a plan of care. This interdisciplinary support eliminates communication barriers and treatment excess, and promotes smooth transitions between health care facilities and home. In addition, the psychosocial support provided promotes Ashley's independence, coping skills, and guides her medical decision making for Cody.

Our medical providers maintain continuity of care and preserve relationships with caregivers and community providers when transitions occur between service lines because they cover both hospice and palliative service lines. As Cody grew, he outlasted his initial prognosis and his decline plateaued. He made the transition to palliative care with HOH, which offers routine visits with a medical provider and nurse case management support for care coordination. Consultations with pediatric-trained social workers, chaplains, child life specialists, and registered dietitians were provided on an as-needed basis. The palliative care team serves as an extra layer of support alongside the child's medical home and subspecialists but does not take the place of a primary care provider or subspecialist. Like hospice, medical providers provide medical guidance, attend subspecialty visits with patients and families to promote joint formulation of plan of care, and routinely communicate with inpatient teams surrounding hospitalizations to assist with transitions.

Cody's shift to palliative care necessitated a heavier reliance on community providers. Ashley no longer had frequent skilled nursing visits or access to on-call support. This transition is challenging for both the family and HOH team as it may occur quickly based on the hospice benefit period end of episode date. Occasionally, social work, child life, and chaplain services are continued at less frequent intervals, though this is not always possible and is a current limitation of the program. Other programmatic challenges include the inability for partnering institutions to review HOH medical records.

For children whose time with HOH ends in natural death, we provide in-home support leading up to and at the time of death by our skilled pediatric team. Funeral planning often begins at the time of admission, though this varies widely based on a child's prognosis, treatment plan, or goals of care. This facilitates a smooth transition from the time of death to the bereavement phase of support. Our multidisciplinary bereavement team provides support throughout the 13 months following a child's death. During this period, families receive support in various ways, including bereavement support groups, bereavement camps for siblings and families, and acknowledgement of firsts, including first birthday, holidays, and other significant family dates.

Unlike many children, Cody's disease trajectory improved and stabilized, and he was discharged from hospice for a life expectancy of greater than 6 months. While Cody's medical complexities and disease trajectory will likely result in future decline, hospice graduation was a cause for celebration and a time to ease fears about the future. Our multidisciplinary team organized a small gathering to look back at Cody's journey and celebrate his future, as we do with all children who graduate. Led by child life, Cody's celebration included keepsakes for Ashley and Cody, a graduation certificate and balloons, and a celebration of his life and future. In addition to celebration, the gathering was also a time to ease fears and instill confidence in caregivers. Many children move between the two

services lines throughout their time with HOH, especially if services are introduced at the time of diagnosis. For Cody, the HOH team always stands ready to readmit him to hospice if needed.

While services and outcomes vary for the patients we serve, the right of families to receive care and support despite challenges like proximity to health care and living in rural, poorly-resourced areas of South Carolina is the same. Challenges in care delivery experienced due to rural or poorly-resourced areas are not unique to South Carolina. In addition to supporting staff development, participating in a state collaborative and engaging payors and legislators in discussions about concurrent care delivery are key steps to overcoming program and community challenges. Hands of Hope is privileged to serve these families and strives to continuously improve our model of care so that all children and families in our state facing life-limiting or life-threatening illnesses have access to quality care focused on improving quality of life.

# The Red Balloon

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The National Consensus Project defines palliative care as an interdisciplinary care delivery system designed to anticipate, prevent, and manage suffering and optimize quality of life in any care setting. There is a deep need for the relief of not only physical suffering, but also of psychological, social and spiritual suffering as well for the patient and the family. Historically, the complex medical and psychosocial needs of children with chronic illnesses in palliative have fallen on the care team within the pediatric hospital system; however, this can potentially create gaps in care as many children in palliative care travel frequently between hospital and home. There is often uncertainty of how long a child will be hospitalized and conversely how long they will get to be home. If a family is unable to relocate, the sheer distance traveled can exacerbate the time spent in either or both locations as to minimize financial and travel burden. The following case study will provide insight into the opportunities that community-based palliative care support programs can provide within the home environment to enhance and further the goals initiated by the hospital and explore the importance of collaboration and providing space for children to participate in their plan of care.

No one plans for their child to be starting kindergarten while simultaneously traveling out of state for cancer treatments. Further, no one prepares for the possibility of having to divide the family system for weeks at a time to accommodate the demanding schedule that comes with pediatric cancer. For Seth,\* this became a reality for his family as he often had to fly back and forth between hospital and home with one parent while his sibling and other parent remained home. He was referred to home-based palliative care as the family recognized the need for extra support when he was home to monitor his constantly changing health, for his parents who were dealing with increased stress, and for his sibling who was having difficulty understanding the near constant-need for travel and why Seth got so much attention. Upon assessment, it became clear that these needs would need to be addressed.

The home-based palliative care program worked in conjunction with the hospital to navigate what bloodwork, vitals, and equipment would be needed to care for Seth when he was home. There were several instances where the ability for bloodwork to be taken at home by the pediatric palliative care registered nurse eliminated the need for Seth and a parent to fly out to the hospital at all; thus, creating more opportunities for the family to remain home together and decrease disruption. Through monitoring 2-3 times per week by the pediatric home nurse, there was not only more data to support if hospital intervention was necessary, but it also provided more data in support of the treatments he was receiving at the hospital.

From a psychosocial perspective, the support that was able to be offered within the home was invaluable in aiding the family in their ability to cope, communicate, and plan. The pediatric social worker was able to fully focus on supporting the parents and integrating in marriage and family strategies to combat the increased stress on their partnership. The sibling was able to get 1:1 attention to address increased stress, feelings of abandonment, and bereavement from a child-based bereavement counselor. The pediatric music therapist was further able to work with Seth directly to support his needs in identifying and coping with emotions, providing an appropriate outlet for expression, and completing legacy projects. Each home-based discipline was able to collaborate to better



support the family all while keeping in communication with the hospital's team to provide insight into the home dynamics to better support them in the hospital as needed. The increased support at home offered security for the hospital team as they knew that needs were being met and that there was continuity of care.

As Seth's medical needs became more critical, the decision was made to have a longer than typical hospital stay during their next trek out of state. It became apparent that this may be the last time he would be traveling to the hospital. Due to the strong relationship between the hospital staff and the home staff, the hospital was able to confirm that the situation had grown increasingly dire. In response, home-based palliative team grew to realize that they may not get to see him again. At his final session, he shared about his fear of dying and missing his family from Heaven. He talked about how he hoped there would be music and silly songs when he got there and his appreciation that he made so many songs with his sibling over the past several months. It was during this visit that he also shared his understanding of the situation, proving once again that children often know much more than we give them credit for. He had two requests—that his family know he will send them red balloons from Heaven so that they know he is safe and okay and that this be shared with them when he dies.

Three months later, a celebration of life was held for Seth with his family and community. A red balloon was brought by the home-based palliative care team, given to Seth's family on their way out. The team shared the story and wish made by Seth during their last visit. It was through tears that his mom verbalized her gratitude and shared that on her way out to her car just after he died at the hospital, she found something special tied to her car door handle—a red balloon.

# Partners for Children – Providing Home-Based Support for Michigan’s Children with Medical Complexity

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In the last 40 years remarkable breakthroughs in medical care have transformed the lives of many children and their families. Conditions that in prior decades were uniformly fatal are now treatable, including prematurity, many forms of cancer, and most types of congenital heart disease. Survivors of these conditions often lead normal or near-normal lives, but many of these children continue to survive only with tremendous daily attention to ongoing medical challenges. In the United States today, almost 2% of all children can be classified as having medical complexity. These are children, who if they had been born a generation or two ago, would not have lived. Now they can, although children with medical complexity require the ongoing care from three or more medical specialists to support their survival. Most also require some form of artificial feeding, mobility aids, and take an average of nine daily medications. They may be challenged by seizures, by respiratory infections, by inability to tolerate their artificial feeds. These challenges regularly lead to crises that result in emergency department visits and hospitalizations. Children with medical complexity currently account for over 80% of the total days spent by children in pediatric intensive care units.

**“We have been so grateful for PFC. It is important to have a provider who really knows our child. PFC has been so diligent in helping achieve quality of life for our family. We are pleased with the program and the providers’ availability to our family.”**

**Asher R.’s  
mom Christina.**

Over the last two decades a number of programs to address the special needs of this vulnerable population have been established—many based in children’s hospitals, some initiated by community hospice organizations, others supported by federal grants. What they have in common have been teams of specially focused clinicians—nurses, nurse practitioners, physicians—who know these children and their specialists well and are dedicated to providing easy access, early interventions when needed, and assurance of communication among the child’s specialists.

In 2018 such a program was launched in southeast Michigan. Partners for Children (PFC) was initiated with a grant from the Michigan Health Endowment Fund awarded to Hospice of Michigan in collaboration with Mott Children’s Hospital. PFC enrolled over 100 children in its first 18 months. Eligible children had either 10 or more specialist doctor visits in the prior year, or had spent much of the prior year in the hospital. On enrollment the child received a home visit from a PFC nurse practitioner and a social worker who remained as the primary contact. Repeat home visits were made every 4 to 6 weeks, and 24/7 phone access was covered by the NP’s and their MD back-ups. The team also included dedicated

“So happy to be included and it couldn’t have come at a better time. Especially in our situation, it is so helpful to have a number to call 24/7 to get advice and/or help. Love that you come to our home and check on our daughter, and make sure we are all OK. Wonderful program. Thank you! Thank you! Thank you!”

**Maison R.’s  
mom Christina.**

“PFC has been an absolute lifesaver for us. They were immensely helpful through our little boy’s surgeries and have saved us countless trips to Mott for various maintenance issues (G-tube and medications). We have found PFC absolutely invaluable.”

**Victor F.’s mom Elena.**

access to other professionals familiar with the children. The PFC team has a dedicated pharmacist, a nutritionist, an education specialist, a rehabilitation specialist, and a pediatric dentist. Parents reported high satisfaction with their ability to call for help when needed and to get advice that was likely to head off a visit to the hospital, and to solve problems to make life a little easier.

A careful review of these children’s utilization of medical services revealed that comparing medical spending before a child’s enrollment in PFC to an equal number of months after enrollment, insurance spending was on average **\$2000 LESS PER MONTH** for each of those children with Michigan Medicaid. Most of this savings came from avoiding or shortening hospital stays. When a PFC child was admitted to the hospital, a team member became involved in the hospital stay and helped to streamline care and assure follow up when the child was able to be sent home.

In March of 2020 the COVID pandemic caused the home visits to be supplanted with video visits. These visits kept families in touch with their team members, and by late 2021, with all staff and most family members immunized, home visits were re-introduced.

Partners for Children has just completed its fourth year. The initial grant ended in 2019, but the Mott Children’s Hospital continues to guarantee its operation for the children currently enrolled, and to add a limited number of new referrals. Expansion of the program to more children and around the state looks promising. A federal program called the ACE Kids Act was passed in 2020 that would allow Medicaid to provide a PFC-like benefit to children receiving their care in Michigan’s other children’s hospitals.

An estimated 1600 children in Michigan have the type of complexity that would enable them to be enrolled in PFC or a similar program. In the boxes are comments from parents of PFC children. A group of health care specialists working in Michigan’s Children’s Special Health Care Services are working on a plan to make this type of service available throughout the state.

For more information about this pilot see [www.mottchildren.org/conditions-treatments/palliative-care/home-based-palliative-care](http://www.mottchildren.org/conditions-treatments/palliative-care/home-based-palliative-care)

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Delivered to: Children's Special Health Care Services Medical Services Administration

Michigan Department of Health and Human Services JULY 2021. Sarah Clark, Lead Investigator Lisa Cohn, Lead Analyst Sara Schultz, Graphics Lead. (A copy of this could be made available if needed.)

# Coordination of Care Between Community Hospices and Pediatric Specialists

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Pediatric patients with terminal illnesses often have a team of pediatric specialists who have seen this patient from diagnosis through treatment. They have been there to provide education, treatment options, and emotional support for the patient and family through their journey. Why does it often feel that once a patient or family chooses hospice this team of specialists is not as involved in the patient's care? Why does the patient and family have to lose these relationships and the support they have provided to them usually over many years? Communication between hospice teams and pediatric specialists doesn't often happen as well as it could, but establishing and maintaining good communication between them can be the crucial element to a smooth transfer of care, maintaining continuity of care, and for promoting optimal outcomes. While hospices are the experts at providing palliation of symptoms and optimizing quality of life, pediatric patients are often medically-complex and can still greatly benefit from good collaboration with the child's specialists.

Hospice of the Panhandle in Kearneysville, West Virginia is a predominantly adult hospice in a rural/suburban area two hours or more away from pediatric hospitals and specialists. This distance places barriers to patients and families seeking specialized treatment for pediatrics close to home. It also places barriers for providers who may want to send their patients home with hospice but are unfamiliar with the options for care that our community hospice can provide or the quality of care the patient would receive. Hospice of the Panhandle has worked to build the confidence in providers, patients, and families that we can be that missing link. While Hospice of the Panhandle (HOTP) does serve pediatric patients, it is a fraction of our patient population. In the last three years, HOTP has cared for 12 pediatric patients compared to over 3,000 adult patients. We recognized the special attention that pediatric patients and their families need and that this was an area of needed growth for the organization, as it is for many adult-focused hospices in the community.

We received specialized training through the PANDA Cubs Primary Palliative Care Training Program from our closest children's hospital, Children's National Hospital, in Washington, DC. We then formed a small group focused on pediatric care at our hospice. This group focused on creating a policy for our organization specific to pediatric hospice care. We used the NHPCO Standards of Pediatric Care (National Hospice and Palliative Care Organization, 2022) as a guide, as well as our combined experience of successes with past pediatric patients. One of the most important pieces of this policy is the focus on collaboration between the patient's pediatric primary care physicians, specialists, and the hospice team. Although our pediatric census is small, we have seen many positive differences since prior to implementing the pediatric policy.

When a pediatric patient is admitted to a community hospice, in addition to getting consents to receive records, you should receive permission from the family to openly communicate with their primary care provider and other specialty providers and hospitals, etc. For the community hospice, understanding the journey of a patient's disease from time of diagnosis and throughout treatment can help the team in many ways. To learn about the patient and family's relationship and the level of trust with their providers, allows the hospice team to understand the dynamics and challenges providers have faced and what strategies were and weren't helpful in addressing these concerns. This also gives the hospice a fuller understanding of how the patient and family came to the decision to choose hospice care.

Knowing why the patient and family chose hospice helps the team begin to form conversations about the plan of care. For example, conversations with patients and families signing into hospice because their primary providers suggested it while continuing chemotherapy will be different than conversations with those whose treatments have not been effective and the patient and family are simply "tired." It is also important to know if their providers have had detailed conversations about prognosis prior to hospice admission. Gaining this history from primary care providers and specialists to help navigate these issues can prove to be vital to a successful hospice experience. It is also known to increase satisfaction and quality of care when the pediatric specialists and community hospice continue to communicate and build trust as the patient seeks treatment and care from both providers (Lindley et al., 2022).

Communication between providers should be initiated at the start of the patient's care with hospice. This allows for communication methods to be established and a rapport to be built between providers prior to any pressing issues or concerns that arise. Hospices should reach out to the primary care providers and pediatric specialists on how each would prefer to communicate. In our experience, email has been successful because of the ability to alert the whole team through one platform. We use email encryption software so that we can communicate via email with full disclosure. This way, the community hospice can send providers regular updates on the patient after visits, and vice versa, to maintain an open dialogue. The hospice team can use this communication to reassure the patient and family that information is being shared between all providers which can relieve the burden for parents who feel the need to do this themselves (Boyden et al., 2021). This also builds confidence between providers and the hospice that quality care is being provided in addition to ensuring consistent messaging between the providers and the patient and family.

Concurrent care laws allow pediatric patients to continue to receive care from specialists for aggressive care alongside comfort care with hospice services, but conversations about concurrent care are vital and must always be carefully negotiated between the hospice and the providers. This is not only to determine who will be paying for individual treatments and medications, but from the hospice perspective as to what might be considered too aggressive based on the patient's current condition and goals. The hospice team must always know the full scope of treatment the patient is receiving from specialists, but when this is reported by families, the hospice is often not given important details of the treatments and the options suggested by their providers. Consulting directly with the provider gives the hospice staff the opportunity to ask important questions, give congruent education to the patient and family, and to ensure hospice philosophies of care are being supported throughout treatment.



Working together, the whole care team can often come up with a plan that is easiest on the patient, that carries the most benefit versus any burdens of treatment, and that agrees with the patient's wishes.

For the pediatric specialists who continue to treat the patient, it is important to note that the hospice team members are constantly having conversations regarding goals of care with the patient and family and these goals can change frequently. We must always consider and navigate the wishes of both the patient and family, and then communicate this to the pediatric specialists as these goals change. This sharing of information between providers can help both teams address all concerns and any conflicts between caregivers to streamline the patient's goals and wishes.

Terms such as aggressive, curative, and palliative, are sometimes defined differently by specialty providers and hospice providers which can also create a point of conflict. For example, a Radiation Oncologist may recommend palliative radiation which could simply mean to them that it is not intended as a curative treatment but is intended to extend life for a few to several months. To a hospice provider, the goal of palliative radiation would be to target challenging symptoms that would help provide the patient with a better quality of life. Hospices value true informed consent and share with the patient and families all known potential risks and benefits of any treatments being considered. For some hospice patients, this can be as basic as discussing the risks and benefits of traveling to their primary provider's offices for appointments or getting frequent/routine blood work and other diagnostic tests that they may no longer want or that have little benefit. At times when families choose to forgo any further testing and treatments, the hospice team might be the one to communicate this to specialists to relieve the burden of the family feeling like they are "disappointing" a provider. When hospices and providers have open communication, hospices can have more meaningful risks and benefits conversations, as well as practice more consistent messaging with less chance of the family feeling like their hospice team and their providers are in conflict. We have also found that increased communication between the specialists and the hospice team has decreased the number of pediatric patients that revoke from hospice care to seek treatment, sometimes dying shortly thereafter in a hospital far from their home and their family/community support systems.

Helping to align patient goals with ongoing treatments provided by the specialist is another benefit of care coordination. Oftentimes there are interventions that can safely and more comfortably be completed in the home setting or at a local facility instead of the patient and family having to travel. Below are two simple, yet very impactful examples of where good coordination of care between providers resulted in a positive patient outcome.

A patient in our program required intravenous anti-emetics via her implanted port. Her primary pediatric physician had scheduled the family come in to the clinic 1.5 hours away to have this completed. The physician's office was not aware that we could complete this intervention safely in the home and save the patient and family from driving 90 miles to have the port accessed. In addition, we suggested to the specialist that a thoracic Pleurx drain be placed so that we could drain Pleural Effusions in the home to help relieve debilitating respiratory symptoms. The specialist took some time to research the intervention and then responded that this was a "brilliant idea." The nurse was able to take information and even samples of the catheter and drain kits to show the patient and the patient's mother what the procedure would entail, and they both agreed to the procedure. The outpatient procedure was quickly scheduled by the provider, and during the journey home the patient felt such relief and joy that she requested to stop at a favorite restaurant and was able to enjoy a meal for the first time in weeks. She was equally happy that she could receive regular draining's in the comfort of her own home, whenever she requested them, instead of having to schedule appointments and make a 3-hour round-trip drive to do so. One of the goals of pediatric hospice care is to reduce hospitalizations and increase "normalcy" as much as possible. We must always strive to bring joy to the child's life and demonstrate that we are helping them to have a life they feel is worth living (ELNEC Project Team, 2021).

Hospice teams observe patients in their home environment which adds a whole new dynamic and point of view that the team can share with specialists who do not see the patient and family in their living environment. Psychosocial or environmental barriers may be more evident when visiting a patient and family at home and can greatly impact their ability to participate in and successfully continue certain types of treatments. Sharing this insight can be very helpful to the pediatric specialist as they continue to coordinate care and discuss treatment options. Since the patient and family are often more at ease and more open in their home environment, the hospice team can observe the family as a whole unit, and learn their likes and dislikes, hobbies, etc., during these intimate home visits. Hospices can explore more thoroughly events the patient wishes to attend or a goal they may wish to accomplish and can dedicate more time and energy to help bring them to life. Coordinating and sharing these experiences with the specialists also allows them the satisfaction of seeing a child's end-of-life goal met and is yet another advantage of close collaboration.

In summary, careful coordination between community hospices and the child's providers allows the hospice team to better understand the patient's journey and how to navigate challenges as the child's disease progresses. Prior to the creation of Hospice of the Panhandle's Pediatric Care Team and pediatric hospice care policy which includes the importance of close communication between providers, this was not prioritized. As a result, it was often very challenging trying to communicate with primary care and specialist providers. Focusing on open communication with the other specialists and care teams, who have been caring for the patient for what is often years prior to hospice admission, allows the providers to still be able to follow, share their experiences, and to have the opportunity for their own closure and this should be prioritized. Even once the patient enters their last days, hours, and following death, the hospice team should be reaching out to provide updates to the specialists who have continued to be involved throughout their hospice journey. This way, providers can hopefully begin to view their young patients dying comfortably in their own home, or closer to home, as an optimal outcome instead of simply as a "failure of treatment." Concurrent care can be challenging, but it is a beautiful provision, especially when artfully negotiated between hospices and pediatric specialist providers. With providers sharing information and having a united front with a consistent message, the patient can remain at home with goals that can be met that allow the pediatric patient to have a life worth living for the time that they have remaining.

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# Accessing Medications in the Community for Children Receiving Hospice Care

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Many families choose to spend their child's last days in the home setting. Understandably, patient comfort and being surrounded by loved ones (including siblings who may not be able to visit in a hospital setting) is a priority, focusing on quality of life and patient comfort.

Providing comfort involves relieving common end-of-life symptoms (as well as possible), such as pain, shortness of breath, nausea, and constipation. Most patients require medications for symptom management. While mail order pharmacy is convenient for maintenance medications the patient is receiving, medications may be needed more urgently as patients decline and symptoms become more significant. Patients may not be able to wait two days for medications to be delivered. Obviously if the patient has an acute increase in pain or other symptoms, families will want medications without delay. Access to medications in the community is essential to provide a high level of care for these patients. Families need pharmacies with convenient locations and hours.

Unfortunately, pharmacies may not carry typical hospice medications. These medications aren't often dispensed to the general population, so it isn't always financially justifiable for pharmacies to keep them in stock. For example, pharmacies may not dispense morphine liquid to patients other than those receiving hospice care. This is even more challenging for children since they may require a less concentrated formulation (morphine 10 mg/5 mL vs 20 mg/mL) to ensure the dose is accurately measurable. Even pharmacies that carry morphine liquid may not carry multiple concentrations. Having multiple formulations also increases the risk for error (possibly selecting the incorrect formulation). Measuring liquid volume and ensuring doses are measurable is an added step for the pharmacist as well.

Ideally, hospice teams will develop partnerships with pharmacies willing to order less commonly dispensed medications. A successful partnership between a hospice agency and community pharmacy optimizes patient care while also providing a new potential revenue stream for the pharmacy. Once a relationship is established with a pharmacy, they are more likely to carry these medications regularly, otherwise it may not be financially justifiable stocking these medications they don't dispense often.

Using the same pharmacies regularly also allows your team to provide education to the pharmacy staff, increasing their comfort level dispensing these medications. Especially in children receiving Concurrent Care. Pharmacy staff must understand which medications will be covered by the hospice versus which medications are still being covered by the primary insurance through Concurrent Care. This adds an extra step for pharmacies to alter which insurance is being billed for each medication.

Section 2302 of the Affordable Care Act, termed Concurrent Care for Children (CCC), allows children less than 21 years of age to receive curative-focused or life-prolonging care concurrently with hospice care.<sup>1-2</sup>

Most symptom management medications will be covered by hospice, especially if the symptom is a key hospice symptom of pain, nausea, agitation, or constipation. The exception is if the symptom was caused or exacerbated by a life-prolonging, curative-focused, or disease-directed therapy; then Concurrent Care is appropriate. Ensure appropriate documentation regarding coverage decisions. Therapies that are considered life-prolonging, curative-focused, disease-directed, maintenance, or prophylaxis are appropriate for concurrent care coverage. Meanwhile, the hospice will be responsible for managing typical hospice symptoms, such as pain, nausea/vomiting, agitation, and constipation.

Concurrent care may be a new concept for pharmacies. They may not realize children still qualify for the added layer of hospice support while continuing to receive life-prolonging therapies, such as chemotherapy or immunosuppressants. Pharmacy staff will need to be notified that the patient is receiving Concurrent Care and that medications may be billed differently. They must know which medications are covered by hospice versus which are still being covered by the primary insurance.

Developing an interdisciplinary collaboration between pharmacists and providers allows for an added layer of support for drug and dose conversions, especially for children with weight-based dosing and different swallowing abilities. Children may need different concentrations of medications, compounded liquids, or crushed tablets. Additionally, needs will change as children grow. Pharmacists can explore alternate drug delivery methods, especially in shortage situations. Drug shortages can have a significant impact on hospice patients. Obtaining appropriate medications is even more challenging when pharmacies can't order specific medications.

As patients decline, evaluate deprescribing to better meet the patients' goals of care and prognosis, minimizing pill burden, unwanted adverse effects, and potential drug-drug interactions.

Hospices that partner with a pharmacy benefits manager (PBM) may have additional resources to help them locate difficult-to-find medications locally. Relationships with compounding pharmacies are especially important when medications aren't commercially available in a formulation that allows for measurement of a child's dose.

The Institute for Safe Medication Practices (ISMP) developed a list of high-alert medications in the community/ambulatory care settings.<sup>3</sup> Many pediatric hospice medications appear on this list:

- Antithrombotic agents
- Chemotherapy
- Immunosuppressants
- Sedating medications
- Opioids (all routes)
- Pediatric liquid medications that require measurement

To stay compliant with ISMP recommendations, pharmacies must standardize their prescribing, storage, preparation, dispensing, and administration of these medications. Patient education must be provided upon dispensing. Once again, another added layer of complexity for pharmacies.

Hospice teams should be proactive in preparing for patients' symptoms as they decline to ensure appropriate medications are available in the home when needed. Adult hospices may use comfort kits; however children require patient-specific medications and doses. A one-size-fits-all kit won't be appropriate for all children. Not only do children require weight-based dosing, but pediatric patients may also require different formulations based on their dose. And there are age restrictions with some common hospice medications. For example, while haloperidol is often used to manage nausea/vomiting in adults, it is not recommended for use in children less than 3 years of

age. Thinking ahead to what medications patients may need as they decline allows time to obtain the medications from the community setting or mail-order pharmacy.

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# Community Partnerships are Indispensable Partners for Successful Hospital-Based Pediatric Palliative Care Programs

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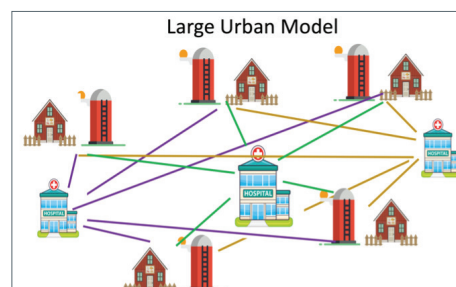
Pediatric palliative and hospice care has seen exciting development over the last 25 years as highlighted in the 50th ChIPPS newsletter.<sup>1,2,3</sup> Many aspects of our field have benefited from expert development, growing gradually away from their origins in adult and pediatric cancer care into an independent field impacting all areas of pediatric medicine. One area which has received less attention is the crucial relationship between hospital-based teams and their community partners.

From an historic perspective, hospital-based pediatric palliative care programs began to emerge in the mid-1990's. Sue Huff and I along with other forward thinking individuals developed the Essential Care program at the Children's Hospital of Buffalo. We realized that our capacity to provide in-patient care would fall short of the patient and family needs without organizations in the community who were willing and able to care for our patients when they were discharged. In that era in western New York, there were scattered adult organizations which were willing to care for children following discharge. Most referrals were for cancer-related diagnoses, which adult hospices felt they could get their minds around and deal with as if our patients were little adults. There were few pediatric amenities in those programs, but they provided nurses who were kind, compassionate, and well versed in caring for dying individuals. We were happy to find organizations willing to care for our patients in that era before concurrent care made children's hospice care financially viable. Back then, families had to choose between hospice care or curative, life-extending efforts. Thus, by the time hospice referral occurred, it tended to be a one-way process. It sometimes felt as if our patients disappeared in a black hole following discharge. One of my earliest recollections in the mid-90's was the lack of communication with the community hospices which applied an adult model to our pediatric patients. There was no sense of expectation to communicate with the referring hospital and it was common to find out only incidentally that a patient we had referred previously had died with no notification of the referring services.

To address the communication hurdle, we took a pro-active approach in Chicago in the early 2000's by developing a collaborative relationship with the primary community providers of hospice services for children. The Chicago children's healthcare landscape was complex with seven tertiary children's hospitals and a dozen well-meaning community organizations willing to care for children, although only a few supported a pediatric team (see graphic right). This initiative, under the visionary leadership of Mary Runge and Kim Downing, developed into the Greater Illinois Pediatric Palliative Care Coalition (GIPPC—[www.gippcc.org](http://www.gippcc.org)).



Around the same time that GIPPCC was forming, the Children's Hospital of Philadelphia published a report on their *Partners in Pediatric Palliative Care* program which demonstrated the value of hospitals and community organizations working together,<sup>4</sup> an initiative which may have had its roots in NHPCO's and CAPC's recognition that *"new approaches are built on partnerships between the hospitals and hospice programs, tapping the expertise of both partners, emphasizing an interdisciplinary approach to care and extending patient- and family-centered, supportive palliative care to seriously ill hospitalized patients earlier in their illnesses."*<sup>5</sup>



Since the introduction of concurrent care in 2010, the value of partnerships has become even more important. A recent analysis of our own center has demonstrated that utilizing concurrent care to allocate costs to primary insurance when therapy is disease-directed and curative in intent rather than to the hospice benefit allows organizations to provide cost-effective care,<sup>6</sup> leading to program sustainability and enhanced care. However, the availability of concurrent care also creates new challenges for pediatric community-based hospice care which must meet compliance expectations for ongoing care and re-certification.

The advent of concurrent care has eliminated the necessity for parents to choose between disease-directed and supportive hospice care. Pediatric providers refer early to palliative care services which forms a central element of our approach to children with incurable illness. However, the nagging insistence of a life expectancy less than six months for hospice eligibility is antithetical to the concept of both early referral and the anticipated life extension families seek through disease-directed interventions. Children live better and longer when receiving expert supportive services, and many of our patients live well past the six month life expectancy imposed by the Medicare hospice definition. Because parents commonly will not forgo attempts to extend their child's life or cure the disease, children referred for concurrent hospice care are living longer than the natural, untreated disease process would have allowed, which is exactly what parents desire. This reality creates an emotional catch-22 for providers who must certify patients as hospice eligible.

Our program recognized that many children with chronic, incurable, often degenerative conditions can benefit from concurrent care and will live longer and better as a result. Recognizing that life expectancy without receiving disease-directed, life-prolonging interventions would be less than six months in most cases should encourage physicians to rethink their criteria for pediatric certification of a terminal illness. *This is entirely consistent with "the natural course of the child's (untreated) disease"* as defined in the Medicare hospice eligibility concept. Some states prior to ACA-2302 replaced the six-month life expectancy criterion with a straightforward requirement that the child have a life-limiting illness<sup>7</sup> which makes far better sense for many of our patients. Illinois and GIPPCC have taken a similar tack in their recent Senate Bill 2384.

To demonstrate the value of partnerships, the following will describe the evolution of a contemporary, community-based, middle-to-large size pediatric program. Our goal was to create **a program without walls** that allowed children to move freely between home and hospital with attention to continuity and open dialog between home and in-patient settings.

**Figure 2** depicts the organic evolution our program from a single hospital and community partner in 2017. The hospital team led the way in reaching out to partner with the community organization which had dedicated their staff and support to the new pediatric initiative. Significant effort was invested initially as volunteer pediatric medical directors to support growth of the community program and create a seamless conduit for bidirectional sharing of information. The foundation of the partnership rested on biweekly IDTs held virtually. This approach provided a transparent segue when COVID hit in 2020 to providing virtual rounds across a large geographic region without the need for in-person IDTs. While each of the community-based teams were initially under the adult medical directors in their regions, the pediatric inpatient director provided expert guidance. Over the next year, all regional pediatric teams fell under the umbrella of the central pediatric medical director who had previously been the inpatient palliative care director. Leveraging teleconferencing via Zoom, virtual IDTs continued throughout COVID as the census grew. Care

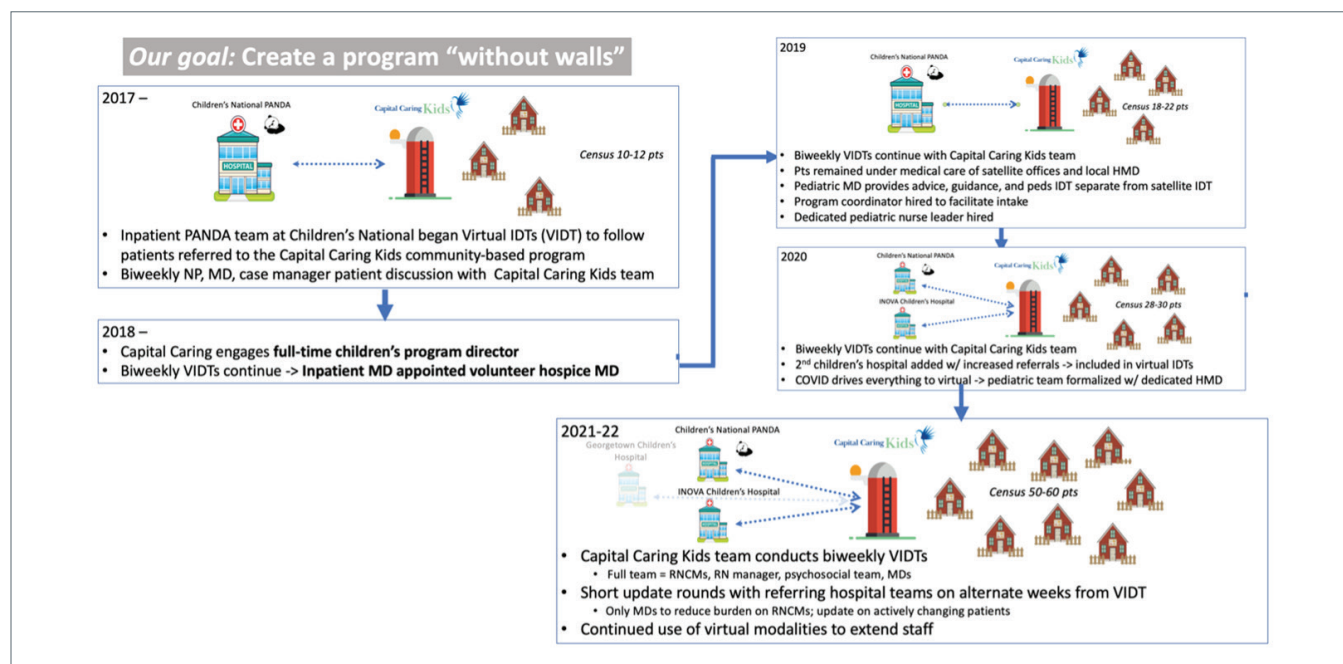
conferences both inpatient and at home were conducted virtually, and the pediatric medical director provided administrative and medical oversight for all pediatric patients. As shown in the figure, a second children's hospital was added in 2020 with services provided to a third hospital a year later corresponding to the increased census.

The hospice team benefited from a dedicated, full-time executive director and a full-time clinical coordinator providing informational visits to prospective patients and processing the myriad documents for patient intake and compliance. A dedicated nursing director was added and a survey in 2021 indicated that nurses found the organizational structure helpful. This structure has continued to evolve into a cohesive team utilizing HIPAA-compliant texting, pictures, email, videoconferencing, and telephone as needed to provide immediate access to physician leadership. Our virtual IDTs typically last 3-4 hours covering up to 60 patients across the entire region. Each region and nurse are scheduled for specific blocks of time. This approach has allowed us to stick to a tight schedule and not tie up team members' time for patients they are not following. Communication and updates to referring hospital teams occurs on the alternate weeks on a recurring basis.

The value of the partnerships established early on with the referral hospitals and with our third party payers cannot be overstated. All parties aim to improve healthcare for children with incurable illness in a comprehensive but cost effective manner. To this end, an open, collaborative dialog is essential to avoid conflict with payers and provide children the services they require. Careful documentation of the hospice-specific services we provide and distinguishing those services from subspecialty care or private duty nursing is critical. Table 1 shows a delineation of services between hospice and private duty nursing. Another important point is that programs cannot be replicated in a new institution and must grow organically as staff and census permit. Like all living entities, each program is unique based upon the team members, their strengths, and the institutions they operate in.

In conclusion, we have presented a model of concurrent care for children recognizing that they will be discharged, readmitted, and discharged frequently as parents seek to extend their lives, improve the quality of time remaining, or seek curative measures. Most will survive more than six months thanks to concurrent care. The model creates an open dialog between care providers in the hospital and community which reduces hand-off errors and creates a transparent program based upon the unique contribution of each. Parents appreciate knowing that all members of their child's care team are talking with one another, which enhances trust and rapport. Suitable for use in many community and hospital settings, the model depends on the willingness of organizations to become full partners.

**Figure 2. Depicting Temporal Program Growth**



**Table 1. Delineation of Duties—Private Duty vs Hospice Nurse**

Private Duty Nurse	Hospice Nurse
<ul style="list-style-type: none"> <li>■ Perform comprehensive assessment targeted to neuro, cardiac, respiratory, GI, skin, and pain every shift</li> <li>■ Provide medications to patient as ordered and document with focus on disease-directed medications</li> <li>■ Monitor continuous positive pressure ventilation via Astral 150 ventilator</li> <li>■ Provide feeds via NG-tube as scheduled</li> <li>■ Accompany parents as needed to physician appointments to support safe transport of the baby</li> <li>■ Vital sign assessment every 4 hours; Temp, Resp, HR, Pain</li> <li>■ ADL' personal care every shift as needed</li> <li>■ Weight measurements: weekly</li> <li>■ Length measurements: weekly</li> <li>■ Head circumference: weekly</li> <li>■ Monitor safe use of oxygen and pulse oximeter</li> <li>■ Assess and instruct parents as needed:</li> </ul>	<ul style="list-style-type: none"> <li>■ Bi-weekly comprehensive assessment per hospice standard assessing for disease progression/ respiratory failure/seizures/nutritional status/ tolerance of respiratory support/skin integrity/ functional status</li> <li>■ Responsible for bi-weekly comprehensive IDT presenting and updating</li> <li>■ PRN visits as needed for status change Medication management and reconciliation of meds through Delta Pharmacy with focus on hospice medications to avoid adverse interactions with disease-directed medications</li> <li>■ Coordinate care with HMD hospice physician.</li> <li>■ Assist with Care Coordination with PCP and specialists: Neurology, pulmonology, nutrition, GI, Cardiology</li> <li>■ Support parents in establishing Goals of Care including comfort measures and limitations of support</li> <li>■ Support parents in end-of-life decision making</li> <li>■ Assist parents with POST/DNR/DNAR as appropriate</li> <li>■ Optimize quality of life measures</li> <li>■ PRN visits for symptom management</li> <li>■ End-of-life symptom management</li> </ul>

## Table Legend:

Responsibilities of the concurrent care hospice nurse are carefully delineated to avoid duplication of services with private duty or other skilled nursing care in the home.

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# A Model of Integrating Home-Based Care Into Palliative Care for Children with Medical Complexity

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The growing population of children with medical complexity (CMC) range from those who benefit from a palliative care approach to those for which it is completely essential. The expansion of CMC in all pediatric settings arises from improved neonatal survival of extremely premature infants and those with congenital and other chronic conditions. Furthermore, new life-saving interventions coupled with an expanding array of technologies in the home setting bolster longevity in conditions once thought to have predictably limited survival (Cohen et al., 2011). Simultaneously, pediatricians are developing a broader appreciation of the benefit of a palliative care approach for all children with life-limiting illness from initial engagement with health care or at diagnosis.

Current pediatric palliative care (PPC) originates from hospital-based PPC programs or community-based hospice programs. Access to inpatient PPC has grown in the past 25 years—from 33% of pediatric oncologists reporting access to a PPC team in 1998, to 60% in 2005 and 70% of US children's hospitals in 2012 (Kaye et al., 2015). Additionally, the majority of the PPC teams providing data to National Palliative Care Registry through 2018 first started enrolling patients during or after 2010 (Rogers et al., 2021).

LJ is a 6-year-old boy with a seizure disorder, developmental disorder, short-gut syndrome due to extensive bowel resections in the neonatal period, advanced liver disease due to lifelong TPN dependence and intermittent GI and other mucosal bleeds attributed to liver disease. He has intermittent issues related to pain, irritability and behavioral concerns—all of which improved after his TIPS procedure several months ago. His parents worry about his quality of life due to symptoms as well as frequent and prolonged admissions with separation from the family. He has a 2-year-old brother who adores him and he adores as well. The parents routinely divide responsibilities and alternate between caring for each child. Extended family has been limited in their ability to assist due to Covid.

Our team approaches the care of CMC with a focus on the integration of specialty care, primary care, and palliative care including home-based care, as well as safe and comfortable transitions between inpatient and

outpatient care. We offer a unique way to meet the evolving, complex, and challenging needs of a growing population of CMC for whom a palliative care approach is essential. This enables us to overcome many common barriers to accessing PPC.

In the community, palliative care services typically depend upon access to a hospital-based team with limited outpatient services or a hospice program that accepts pediatric patients. Barriers to access remain abundant despite the expansion of PPC programs in the inpatient setting. Even for inpatient, the majority of inpatient programs report inadequate staffing to meet the clinical needs of referrals (Rogers et al., 2021). Therefore, hospital-based teams rarely have sufficient resources to extend into the outpatient setting. The hospice options are often run by adult Palliative Care providers who have low pediatric censuses (and do not develop necessary skills to care for children) and rarely have extensive palliative care services outside of the hospice model (for children without death anticipated).

Furthermore, primary teams are often not willing to refer and/or families/patients may not accept referral. The perception of hospice as “giving up” persists for providers and families. Finally, poor reimbursement or support for pediatric palliative care impedes the development of comprehensive, high-quality PPC services across settings (Kaye et al., 2015).

LJ had most of his routine visits with the Complex Care program via telehealth while he continued to see his GI and hematology teams at another institution and had limited contact with his Neurologist at a 3rd institution. Yearly home visits incorporated the administration of routine vaccines. Symptom co-management continued between the primary and specialist teams. Goals of care and advance care planning discussions included his primary caregiver routinely and both parents every few months. Based on those discussions, the team worked to limit hospital admissions with careful care plans, home-based blood tests, and careful review of the risks and benefits of hospitalization versus remaining at home, as symptoms progressed.

In July 2013, we started the Pediatric Visiting Doctors and Complex Care Program at the Icahn School of Medicine at Mount Sinai. We identify and work towards goals of care while engaging in a high-level interdisciplinary approach to decision-making, providing routine primary care, and managing a variety of symptoms to maximize function and quality of life. A unique aspect of our program is provision of medical care at home for some of our patients. Our catchment area is roughly 3 miles around our institution, within which we provide primary and urgent care at home. The care we provide at home includes taking vital signs, providing vaccinations and developmental and psychosocial assessments. The program also has access to perform radiographs, phlebotomy, and obtain laboratory specimens at home when needed. We can also attend specialty appointments at the hospital or telehealth visits to enhance access and improve care coordination and collaboration. Outside our catchment area, we sometimes offer yearly home visits or home visits to assess the environment.

The patient populations we care for at home include high risk newborn as well as CMC. High risk newborns (born at less than 30 weeks gestational age or a serious perinatal conditions requiring close follow-up) remain within our program for 6-9 months after neonatal intensive care unit (NICU) discharge. Subsequently, they either transition to a general primary care pediatrician or to the CMC arm of the program. Infants from the high risk newborn arm or other patients are eligible for the program if they meet any of our criteria: two or more complex chronic conditions (excluding routine childhood conditions such as asthma or obesity and behavioral or psychiatric conditions), one major medical condition that involves multiple organ systems, technology dependence (feeding tube, tracheostomy, respiratory support, wheelchair dependence, etc.), or an immediate palliative care need (a new diagnoses, significant clinical deterioration, or hospice referral).

From July 2013 to April 2019, we conducted 622 home visits (representing 42% of our encounters) for 121 patients. The majority of patients identified as non-white (93%) and 47% Hispanic. About 90% of patients had public



insurance as their primary and about one-third of patients were non-English speaking. Around half of the patients use a feeding tube, and over 40% are wheelchair dependent. Enrollment in our program was associated with decreases in all of the following: Emergency Department (ED) visits, hospitalizations (planned and unplanned), lengths of stay in the hospital, and 30-day hospital readmission rates—the decreases in the lengths of stay and number of unplanned hospitalizations were both statistically significant. Further details of health care utilization outcomes have been published previously (Lin et al., 2020; Tannis et al., 2019). Most important for the program's contribution to the care of CMC with palliative care needs, we found that a higher number of home visits were associated with decreased overall healthcare utilization use after enrollment in the program. This decrease was statistically significant for ED visits and hospitalizations. Our program uniquely addresses common barriers to palliative care for CMC.

LJ eventually enrolled in a community-based hospice program. The family accepted referral upon learning that all current providers welcomed hospice involvement and their services remain unchanged. Home service teams (therapists, teacher, and nurses) overcame hesitation when they witnessed the increased support for the family. The hospice program overcame the previous barrier of ongoing TPN administration with careful coordination with his insurance.

The recognition of our program's expertise in the care of CMC enables meaningful influence with specialty providers and community-based services. Our team's involvement facilitates opportunities to share family/patient goals of care and advanced care plans across teams leaving them feeling empowered, rather than hopelessness or as if they are giving up. Our integrated approach to complex care, palliative care, and primary care alleviates the need for transitions of care as curative treatments are less available and symptoms escalate.

Finally, our team's family-centered approach to complex and primary care provides for the inclusion of healthy siblings within our medical home. The routine health care of our healthy sibling patients incorporates their specific needs and the impact of living with a sibling with a chronic medical condition.

Each year that LJ received his vaccines during home visits, his younger brother XJ had his routine visit and vaccines as well. He participated in both visits. When his brother passed away a few months before his 8th birthday, XJ had a video visit 2 weeks later to review how he was coping and how the family was supporting him. Two weeks later, he came to the office for a routine physical where ongoing support and care coordination were available to parents and the 3 ½ year old. Plans were made for his 4-year visit and the family was welcomed to continue with the team for as long as it was helpful to them.

Many families who experience the death of a child will return to us for 1-2 visits with a healthy sibling and then transition to primary care elsewhere. Others will continue for a few years and occasionally they will stay until the adolescent or young adult transition to an adult care provider. Bereavement is a process that is not linear and our program embraces that fact and the families who live it. While some parents need a fresh start where they are not reminded of their child who died, some seek a place where it remains safe to talk about their child who died or benefit from a provider who will understand when they worry they are overreacting. Our program provides an open model for survivor siblings and their families to pursue the connection and remembrance that matches their needs.

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# A Framework for Transitioning Children with Medical Complexity from Hospital to Hospice Care

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## Transitioning children with medical complexity from hospital to hospice care

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With the rise of medical technology, children with medical complexity (CMC) are living longer and are able to receive the vast majority of their care at home and in their community.<sup>1</sup> Despite medical advances, CMC have high likelihood of death in childhood due to their underlying illnesses.<sup>2,3</sup>

Improving the quality of care of individuals as they transition from hospital-based care to home-based care is a priority for many national organizations. This is because transition across settings can be fraught with delays, errors, and adverse events if there is not a careful oversight of this process.<sup>4</sup> Improvement in these transitions is especially important for CMC at the end of their lives and their caregivers to limit suffering as much as possible.

Hospice care is one of the important services that CMC may receive. Caregivers often desire for the child's dying process to occur at home rather than in a hospital, and hospice agencies help facilitate this.<sup>3</sup> Hospice agencies can provide immense support to families (at home or within a hospice facility) especially when the child's dying process is prolonged. Ongoing relationships with hospice and palliative care providers can help families make decisions about continuing or foregoing life-sustaining treatments.<sup>5</sup>

There are challenges transitioning CMC to hospice care. First, pediatric hospice services are not easily available.<sup>6</sup> Even when hospice agencies agree to provide care for children, these agencies may not provide the breadth of services that CMC need. CMC often depend on many medications, medical technologies, and services within their medical neighborhood.<sup>7</sup> CMC receive care from many different providers (primary care, specialists, and home health providers) with whom they have long, ongoing relationships. Establishing a relationship with a new agency such as hospice may be difficult for caregivers. Additionally, CMC often have rare medical conditions with unknown trajectories making it difficult to prognosticate.<sup>8</sup> We have seen CMC unexpectedly survive for many months or even years despite an initial prognostication of imminent death. If children survive beyond six months, they may not be eligible for hospice services, even though they still require supportive services. For all the reasons mentioned above, we recommend a thoughtful and methodical approach to transition hospitalized children to hospice care. A hospital-based pediatric palliative care team can facilitate this process. Pediatric palliative care providers have a good understanding of the nuances of caring for CMC. Therefore, they can serve as a resource for continued medical decision-making, facilitate bi-directional communication between hospital-based and community-based providers, and provide ongoing family support.

## Framework for transitioning CMC from hospital to home care

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Based on our clinical experience transitioning approximately 60 CMC across inpatient and hospice settings, we developed a framework and a checklist to guide hospital-based clinicians when transitioning CMC from the hospital to hospice care. In the following paragraphs, we describe the four components of this framework. In the accompanying checklist, we list specific activities associated with each component of the framework.

### 1. Hospice Referral

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When a hospital-based provider encounters a child who is likely to die within the next six months, they should consider referral to hospice. The provider should perform a medical record review to garner greater understanding about the child's medical condition and prognosis, and services used. Prior to discussing hospice services with the family, the provider should explore options for hospice that are available in the child's community. Pediatric hospice services in some areas, especially more rural locations, can be very limited or non-existent. Clinicians need to assess hospice agencies' capacity to care for pediatric patients—availability of interdisciplinary providers with pediatric training, hospice physician's ability to manage symptoms related to the dying process, availability of the breadth of pediatric services, including if there is an inpatient facility should the family prefer that option. The next step is to introduce the concept of hospice care to the family. This is done by establishing the goals, wishes, hopes, and fears of the child (if able to communicate these wishes) and their caregivers.<sup>9</sup> This process may take multiple conversations over a period of time. Initial discussions should include an overview of the child's medical condition, expected prognosis (including if curative treatment is available and if not, discussion of why) and discussion of medical interventions available (including risks and benefits), and the option to not pursue these interventions and focus on comfort. Providers should ensure the caregiver's (and children's if appropriate) understanding, allowing for questions and clarifications. Providers should then align the treatment plan with the wishes of the family and obtain their consent to refer to hospice. In addition to the hospital and palliative care teams, it may be beneficial to include the child's primary care and specialist providers in these discussions.

## 2. Planning for Discharge

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The first step in planning for discharge to hospice is for clinicians to gain a clear understanding of interventions that caregivers agree to pursue and which they will limit (e.g., respiratory support, artificial nutrition, and hydration, etc.). This should also include discussion about resuscitation interventions. Clinicians may need to review and complete the Do Not Resuscitate Order (DNR) or medical orders for life-sustaining treatments (MOLST) form (or state equivalent). A common misconception is that DNR status is a requirement for hospice admission. Additionally, a child with a DNR may still receive life-sustaining treatment depending on the family's wishes.<sup>5</sup>

To develop this discharge plan, hospital-based clinicians need to be cognizant of the differences in the care of children in the outpatient setting.<sup>10</sup> A comprehensive care plan should be developed based on the family's wishes, the child's medical needs, and the scope of practice of the hospice agency. Particular care should be given to transitioning medication management. Hospice agencies will differ in their ability to provide various interventions to manage symptoms. Some may be able to provide intravenous (IV) medications and others may not. Some agencies may not have a pediatric hospice physician to oversee medication management and may need to rely on primary care or specialist pediatric providers. Home health nursing orders, including those for medical equipment and supplies may need to be revised to accommodate for hospice agencies' practices. Clinicians need to be aware of the differences in durable medical equipment (DME) used in the outpatient setting compared to the hospital setting and be mindful of the time it takes to acquire and deliver supplies to a home.<sup>10</sup> It may be necessary for the hospital to provide 2-3 days' worth of medication and supplies to support the family until these can be provided in the outpatient setting. It is also important to clearly establish or negotiate the roles and responsibilities of the many providers involved in the child's care. Typically, hospices can only provide nurse visits at certain intervals to assess the patient, modify the care plan, and educate and support the family. This is different from private duty nursing (PDN) services offered by home health nurses. Because of Concurrent Care legislation, children are eligible for both hospice and home health nursing services.<sup>11</sup> When home health nursing is involved in addition to hospice, there needs to be clear communication regarding what aspects of care PDN can and cannot provide. For example, home health nurses may not be able to administer certain IV medications or manage a patient-controlled analgesia (PCA) pump. Additionally, there needs to be clear communication as to which agency—hospice vs. home health agency vs. DME—will be responsible for providing and maintaining medical equipment and supplies. If these issues are not appropriately addressed prior to discharge, this could increase the risk of adverse events and re-admissions, and lead to significant caregiver burden.<sup>10</sup>

## 3. Caregiver Preparation

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Caregivers require inpatient education and training that corresponds to the newly developed care plan.<sup>10,12-13</sup> Regardless of whether PDN or hospice is involved, caregivers will be required to independently provide medical care at home. Training should include general cares (e.g., feeding, diapering, positioning, etc.), administering medications, and managing respiratory support and other specialized treatments. Training must also include emergency management, such as gastrostomy tube dislodgment, respiratory decompensation, equipment failures, etc.<sup>10,13</sup> Additionally, caregivers should be prepared about symptoms expected throughout the dying process such as pain, anxiety, air hunger, itching, nausea/vomiting, and constipation. Clear guidance should be provided on which provider (and agency) the family should contact if a clinical issue arises. Caregivers should be provided with written instructions that correlate with the plan of care and include relevant contact information for all agencies and medical providers involved.<sup>10,12</sup>

## 4. Post-Discharge Follow-Up

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To ensure seamless transition, following the discharge of the child to hospice, a hospital-based provider should follow up with the family in a timely manner, but one that is respectful of the family and child's situation. This is likely best done by the care coordinator familiar with the family. The coordinator should ensure that the family has all the needed medication and supplies, full understanding of the care plan, and has had contact with the hospice agency and other community agencies. Assessing the family's understanding of the process once the child has died is important. Generally, the hospice agency develops a plan with the family as to what steps need to be taken after the child dies. Additional considerations are aligning this plan with the presence or absence of advance directives, need for Medical Examiner involvement, and family's wishes for organ donation. Finally, should the child survive unexpectedly, or the family changes their goals, the entire team should be willing to revise the care plan.

## Conclusions

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Transitioning CMC from hospital to hospice care is a complex process that requires collaboration between the many providers involved in the child's care. Care coordinators (inpatient team or palliative care team) are essential to ensuring that all the above processes occur and the transition from hospital to hospice is seamless.<sup>14-15</sup> Care coordinators, especially those dedicated to palliative care, are a point of contact for continuity and provide an incredible resource to families and medical professionals. Care coordinators can adapt the checklist that we have developed to their institution's specific structure and facilitate successful discharge of the child from the hospital to hospice. In other pediatric populations with serious illness (e.g., children with cancer), or special circumstances (e.g., compassionate extubation at home) previously published checklists are also available.<sup>16-17</sup>

If hospital-based clinicians understand existing resources for CMC in their community, they can assist in a more seamless transition from hospital to hospice care. As medical technology advances and the healthcare system evolves, there needs to be frequent review of processes related to the care of CMC. These processes should be aligned with the needs of children and caregivers, to improve care and reduce burden on families. Additionally, there needs to be continued support of the development of care coordination services as they are essential to effective transitions. Finally, expansion and improved reimbursement of outpatient pediatric hospice services is desperately needed to support children and their caregivers throughout the dying process in the home or community.

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## Hospital to Hospice Discharge Checklist\*

### 1. Hospice Referral

#### 1.1. Consider hospice referral

- ☐ Consider referral to hospice if patient is likely to die within 6 months AND family expresses desire to have child at home or closer to home at the time of death OR If child may have a prolonged end-of-life (EOL) process
- ☐ Contact palliative care team if assistance is needed. [The goal is to help the family take their child home and/or put a more long-term plan into place in the event of a longer survival time. Avoid rushing discharge. Each discharge is unique and requires careful planning.]

#### 1.2. Review medical record

Review the child's medical record to gain understanding about:

- ☐ Medical condition/diagnoses, and prognosis
- ☐ Current medications
- ☐ Medical technology used currently
- ☐ Existing primary, specialty and support services
- ☐ Household residence

#### 1.3. Identify hospice options

- ☐ Identify which hospices serve the county in which the child lives
- ☐ Does the hospice agency accept pediatric patients?
- ☐ Does the hospice agency have pediatric-trained staff? How comfortable are they with pediatric patients?
- ☐ Does the hospice agency have an inpatient facility?
- ☐ Does the hospice agency accept the child's health insurance?
- ☐ Is the hospice physician able to manage child's care? If not, ask primary-care or specialist physician about managing child's care.
- ☐ What bereavement support services does the hospice agency offer?
- ☐ What is the distance from hospice agency to child's home? [Hospice agencies may have limits on distance to home from agency]
- ☐ For caregivers whose primary language is not English: Does the hospice agency have language interpretation services?

#### 1.4. Discuss hospice option with family

- ☐ Present hospice care option to family
- ☐ Inquire if the family has a preference for a specific hospice agency
- ☐ Discuss family's preference for discharge to hospice inpatient facility or home hospice service
- ☐ Inquire family's preference for involvement of primary-care or specialist physicians in the decision making process.
- ☐ Obtain caregiver consent to make hospice referral

#### 1.5. Make hospice referral

- ☐ Write orders to admit to hospice
- ☐ Contact hospice agency and discuss referral
- ☐ Send orders, referral form, insurance information, most recent notes (include notes related to prognosis).
- ☐ Include list of medications, current medical technology and anticipated equipment needs at home.
- ☐ Notify hospice of existing equipment in home and equipment company
- ☐ Inquire if hospice can come to hospital to meet family if referral is accepted
- ☐ Prepare parents and providers that the plan for discharge to hospice can be delayed or canceled suddenly. [It is recommended that discharges to hospice do not occur on evenings and weekends.]



## 2. Planning for Discharge

### 2.1. Establish code status

- ☐ Clarify family's goals and establish code status. Document conversations in medical record.
- ☐ If applicable, review and complete Do Not Resuscitate Order (DNR) or medical orders for life-sustaining treatments (MOLST) form. [Although preferred, a pediatric patient is not required to have a DNR to be admitted to hospice.]
- ☐ In the discharge summary, describe family's goals of care, discussions regarding limiting scope of treatment and/or resuscitation status.

### 2.2. Develop a plan for medications

- ☐ Determine which medications are to be continued, discontinued, or new at time of discharge compared to admission to the hospital. [Hospice is only responsible for medications that are directly related to the terminal diagnosis.]
- ☐ Determine who (hospice vs. pharmacy) will provide the medications and how they will be provided.
- ☐ If on intravenous (IV) medications, attempt to transition to enteral, oral or rectal if possible.
- ☐ If IV medications are needed, make appropriate plans with the hospice agency.
- ☐ Ensure child's symptoms are well controlled on same medications administered via similar route that will be used in the home.
- ☐ Anticipate end-of-life (EOL) symptoms, such as fever, pain, air hunger, anxiety, itching, nausea, constipation, secretions, seizures etc.
- ☐ In the event that patient-controlled analgesia (PCA) is indicated, and hospice can provide PCA, identify an alternative medication plan for transportation. [Transporting a patient on a PCA is logistically challenging.]
- ☐ For any EOL medications provide dosing recommendations to assist primary-care physician or hospice staff who may not be familiar with pediatric medications.
- ☐ Provide orders for an aggressive bowel regimen.
- ☐ Ensure that patient has at least a 3-day supply of medication at the time of discharge that is available when the child reaches home. [Compounded medications take time for the pharmacy to prepare and not all local pharmacies can provide.]
- ☐ Have a nurse or pharmacist review medications with family before discharge.
- ☐ Write orders for medications, range of dosages, and indicate reason for PRN medicines. Consider generous dosing interval.
- ☐ Consider the dosage strength; medicine that is more concentrated will be easier for the child to tolerate instead of large quantities.
- ☐ Do not order concentration that will make it hard to measure or difficult to obtain.
- ☐ Consider need for prior authorization for Scheduled II medications

### 2.3. Develop a plan for artificial nutrition and hydration

- ☐ Document if family agrees to cessation of artificial nutrition and hydration
- ☐ Consider writing flexible feeding orders: "as tolerated", "per parent discretion", or "stop feeds for signs of intolerance"
- ☐ If tube fed, indicate type and size of feeding tube. Develop a plan for malfunction of feeding tube.
- ☐ Consider order for replacement Pedialyte
- ☐ If using nasogastric (NG) feeds, consider teaching family how to place and order "may place NG at parent's discretion if needed for medications or formula"
- ☐ Discharge with 2-3 days of formula, Pedialyte, supplies in event hospice cannot obtain quickly

### 2.4. Write or revise home nursing orders

- ☐ Write specific home health nursing care orders
- ☐ Review previous nursing orders and adapt for hospice care (i.e. change tracheostomy prn instead of every week)

- ☐ Discontinue lab orders as appropriate
- ☐ Vital signs – determine whether checking vital signs should be discontinued or made less frequent
- ☐ Consider Foley catheter as needed for comfort
- ☐ Write orders “as tolerated” or “at the discretion of the parent”
- ☐ Change routine respiratory orders as appropriate. [Continuous infusions for symptom management are usually managed by hospice and often home health nurses are not allowed to manage them as they are not trained in their use.]

#### **2.5. Develop a plan for medical equipment/ supplies**

- ☐ List all equipment and supplies needed in the home
- ☐ Identify what equipment and supplies are already in the home
- ☐ Consider suction, hospital bed, bedside commode, side table, IV pole, IV supplies (dressing kits) and IV pump, enteral supplies (feeding tube, formula, syringes), diapers, disposable bed pads. [For new equipment/ supplies, hospice will contact their DME to make arrangements.]
- ☐ Determine what will need to be delivered to home vs. hospital room. Find out if someone would be available in home to receive the supplies.
- ☐ If oxygen is needed, order oxygen in range such as “0-5 LPM” and indicate “for comfort only”. Indicate route.
- ☐ Consider discontinuing pulse oximetry. Or, consider orders “pulse oximeter to be used at parent’s discretion”. [Monitoring oxygen saturations is not required, and hospice may not approve use of pulse oximetry if not already in home]
- ☐ Indicate if supplemental oxygen should be humidified
- ☐ Give 2-3 days of supplies due to hospice may not be able to provide at all or immediately

#### **2.6. Establish roles of team members**

- ☐ Negotiate roles of primary-care and specialist providers, home health nurses, and hospital-based palliative care clinicians.
- ☐ Determine who the parent/caregiver should call for specific issues
- ☐ Share providers’ contact information with the family

#### **2.7. Plan for transportation**

- ☐ Determine whether patient will be transported home by private vehicle or medical transportation.
- ☐ Determine whether patient will use car seat vs. car bed vs. physician note allowing family to hold patient if riding in private car.
- ☐ Ensure family has appropriate equipment for safe transport home
- ☐ Plan in event for emergency or crisis in route home.

### **3. Caregiver Preparation**

#### **3.1. Teaching**

- ☐ Ensure parents have basic teaching needed to care for child at home
- ☐ Solicit any questions they may have about EOL process
- ☐ Educate parents about benefits and harms of monitoring (e.g. pulse oximetry). [Pulse oximetry may provide peace of mind for the parent when sleeping or out of the child’s room. It could be a nuisance due to frequent alarms and focus being on machine not child.]
- ☐ Educate parent hospice provider’s roles. [Hospice is different from shift nursing. The hospice nurse makes daily/weekly visits to home to assess patient. Family will be able to call hospice 24/7 for support.]
- ☐ Give contact information for all providers (including home health nursing, DME, hospice and medical providers)

#### 4. Post-Discharge Follow-Up

##### 4.1. Follow up

- ☐ Make follow-up call after discharge. [This can be a role of the primary team or the palliative care team].
- ☐ Discuss plan in the event the patient survives longer than anticipated

##### 4.2. Emergency or Death at Home

- ☐ Educate parents to call hospice in the event of emergency or death. [If DNR/MOLST is in place, a hospice nurse will come to home to pronounce patient. If there is not a DNR/MOLST, the family should call 911 in the event of an emergency or death.]

##### 4.3. Medical Examiner

- ☐ Determine whether this will be a medical examiner (ME) case and contact ME in county of expected death for instructions
- ☐ Prepare for death during transport. If the child dies during transport, the child should be taken to the closest hospital in the county

##### 4.4. Organ/Tissue Donation

- ☐ Consider if the family wishes for the child to be an organ or tissue donor and devise a plan for organ/tissue donation.

# Pediatric Palliative Care's Role in Achieving Health Equity for Children with Medical Complexity

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Children with medical complexity (CMC) are one of the fastest growing pediatric populations in the country. There are now over 1 million CMC in the United States, representing a doubling in size of the CMC population over the last decade.<sup>1</sup> Given their medical fragility, symptom burden, and care coordination needs, pediatric hospice and palliative care (PPC) clinicians have taken a central role in caring for CMC and their families. Furthermore, as the vast majority of CMC live at home with their families, much of PPC clinicians' CMC-focused care has shifted to the community setting. In this article, we discuss how the concept of health equity applies to the intersection of

PPC and CMC care in the community, as well as barriers to and strategies for achieving health equity. This commentary is a summary and adaption of Houtrow et al.'s recent article that accompanies *Pediatrics' special issue Blueprint for Change: Guiding Principles for a System of Services for Children and Youth with Special Health Care Needs (CYSHCN) and Their Families*.<sup>2,3</sup>

It is important to start with reframing our definition of **health** and **health equity**. We understand health not as the absence of disease, but rather the extent to which a child is enabled to realize their potential, satisfy their needs, and interact successfully with their physical and social environment. Health equity is defined as, "the absence of disparities or avoidable differences among socioeconomic and demographic groups or geographic areas in health status and health outcomes." We believe that all CMC, regardless of their circumstances, deserve the opportunity to be as healthy and functional as possible and to thrive in their communities.<sup>2</sup> To play our part in advancing health equity, PPC clinicians must help address and overcome the barriers preventing our field from maximizing quality of life, reducing suffering, optimizing medical decision-making, and coordinating care for all CMC and their families.

These barriers, often referred to as social determinants of health, refer to the context into which CMC are born, live, play, learn, and grow up. When these factors hinder children from fair and just opportunities to thrive, they are oppressive. Regrettably, we know that CMC live at the confluence of multiple oppressive factors including racism, poverty, and ableism. A higher proportion of CMC are members of minoritized racial groups than the overall pediatric population (21.6% of CMC identify as Black vs. 13.2% of the overall US pediatric population). CMC families are more likely to live in poverty (35.4% of CMC live below the federal poverty threshold compared to 20.2% of all US children) and experience difficulty affording food and other basics (e.g., housing).<sup>1</sup> Compared to children with no chronic health conditions, CMC are significantly more likely to experience parental divorce or separation, have a parent die or be incarcerated, and live with a person with mental illness or substance abuse disorder.<sup>4</sup> CMC also have the highest risk among all children to have inadequate health insurance and experience reduced access to well-functioning health systems.<sup>5,6</sup>

Perhaps most importantly, all CMC experience significant disabilities—health conditions associated with functional impairments resulting in activity limitations and participation restrictions. As disability often tracks with the oppressive factors described above, this results in a scenario in which marginalized children and families are also subjected to ableist attitudes prevalent within the health care profession. Families and caregivers of CMC repeatedly tell us that caring for their child entails constantly being told that their child's life is of little value.<sup>7</sup> This bias is expressed explicitly when clinicians only refer to disability in terms of loss and tragedy or provide unprompted recommendations of stopping life-sustaining treatment without careful exploration of a family's values and goals.<sup>2</sup> Ableism is also communicated implicitly, at scale, in how poorly the CMC health care systems are structured and financed. CMC have the highest rates of inadequate insurance coverage and more often live in states that have not participated in Medicaid expansion, exposing many CMC families to high-degrees of financial adversity. Critical yet time- and labor-intensive services such as care coordination remain poorly compensated and disincentivized, resulting in fragmented systems with high administrative burdens.<sup>8</sup> Payors, health care organizations, and governmental agencies continue to undervalue and underinvest in home- and community-based services and workforces (e.g., home health care)—leaving many families of CMC to care for their children with minimal assistance or respite.

With these challenges in mind, we want to highlight that PPC's holistic approach to caring for children with serious illness positions our field to play an integral role in ensuring CMC are as healthy as possible. Doing so, however, requires a commitment to health equity's underlying principles and values as described in the Maternal and Child Health Bureau's Blueprint for Change.<sup>3</sup> In short, PPC clinicians and teams must be willing to dismantle the structural and systemic barriers impeding progress towards CMC health equity. Our field must commit to prioritizing CMC health equity in its attempts to reshape and re-design PPC services. We must also pledge to

accurately monitor outcomes relevant to CMC health equity and foster workplaces that are increasingly diverse and reflect the communities we serve.

There is much our field can do to advance CMC health equity. First, PPC can address the bias in attitudes towards children with disabilities (i.e., ableism) that is not just pervasive in health care, but still persists even among PPC clinicians. This entails adopting and promoting an outlook which recognizes children with disabilities can experience both challenges and joy and fulfill the lives of their families. Families of CMC tell us that caring for their child has provided them with a unique sense of purpose, increased their self-confidence and resilience, and a greater appreciation of life's ups and downs. In other words, our field must help reimagine "quality of life" through the lens of CMC and their caregivers.<sup>9</sup>

Practically speaking, PPC clinicians should advocate for care plans that prioritize outcomes which actually matter to CMC families (i.e., a family-centered approach). For example, instead of focusing treatments on "fixing" a disability, we can help colleagues craft treatment plans that aim to maximize a child's attendance at school or their ability to make and sustain friendships. Leveraging our field's essential role in clinical education, PPC clinicians can also integrate this mindset into educational experiences for students and trainees as well as career development programs with colleagues. Furthermore, within our own ranks, more CMC-specific experiences and education should be incorporated into PPC training so that all PPC clinicians are knowledgeable and competent in basic CMC care.

To help overcome the structural ableism embedded in pediatric health care systems, our field also must focus on improving access to PPC services so that the benefits of PPC are available to all CMC when, where, and how they need it.<sup>8</sup> It is inadequate and inequitable for PPC to de facto focus on children who are able to "come to us" while most PPC teams are situated in academic institutions in urban settings. Instead, PPC must better integrate itself into the communities in which CMC live and enhance its support of local health systems. PPC teams can work with community partners to develop bi-directional information-sharing protocols and formalized co-management plans. To address specific geographic and transportation barriers, PPC teams should also further strategies which adopt and implement remote telehealth services. Such approaches will enhance PPC's capacity to collaborate with community-based CMC clinicians and cooperate with organizations serving CMC outside of health care (e.g., education, housing). For example, for CMC families experiencing financial hardships, PPC clinicians should be better able to connect families to community agencies which assist with (re)enrolling a child in Medicaid or identify organizations that help obtain medical equipment at reduced cost.

We all must also urge leaders in our field to use their positions to advocate for policy- and system-level changes which promote CMC health equity. We should support efforts that lobby payors and health systems to adequately fund the long-term services and supports enabling CMC to thrive in their community (e.g., PPC, home nursing).<sup>10</sup> This funding must be specifically directed to expanding and sustaining the workforce behind such services. Similarly, PPC leaders should advocate for increased investment in the infrastructure needed for enhanced care coordination—mechanisms that enable information sharing and team-based care will reduce the complexity and fragmentation of the CMC health care ecosystem. Our field should also be on the forefront of adopting value-based payment strategies. The time- and labor-intensive activities which define family-centered care, care coordination, and community-based care must be financially incentivized. In return, PPC teams have to be willing to monitor CMC health outcomes and link payments to care quality. We emphasize this advocacy need not exist only at state or federal levels—PPC clinicians can take the lead in promoting payment and structural reforms within their own health system.

Finally, we should highlight that any attempts to improve services, redesign health systems, and alter state or federal health policies will be most successful and impactful if CMC and their families are equal partners in such endeavors.<sup>11</sup> Patients and families, especially those from minoritized communities, must be included in all phases of planning, implementation, and analysis. Given our field's integral role in CMC care and commitment to family-

centered care, PPC teams can help lead elevating and integrating the voices of CMC and their families into efforts to dismantle structural and systemic barriers that perpetuate oppression. While we acknowledge that health equity for CMC and their families is an aspirational goal and that progress will come incrementally, we also believe such a vision is not unattainable.

## Abbreviations

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**CMC** – children with medical complexity

**PPC** – pediatric palliative and hospice care

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# Provision of Pediatric Palliative Care in Underserved Latino Communities

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In the United States, children from underserved communities are known to experience poorer access to health care, more fractured health care, and worse outcomes.<sup>1,2</sup> Adverse social conditions are more prevalent in households of children with special health care needs.<sup>3</sup> Latino children are disproportionately from poorer households, have worse access to health care, and are at increased risk for negative health care outcomes.<sup>4,5,6</sup> This inequality in care for Latinos is heightened in the palliative care setting, where health care needs increase and opportunities for fractured care are more prevalent. Knowledge of barriers to underserved communities receiving palliative care, particularly in the Latino population, is necessary to help minimize the effect of those barriers, thereby improving the access to and quality of the palliative care provided.

The purpose of this review is to outline nuances and challenges to the provision of palliative care for Latino patients and their families. For the purposes of this article, the term "Latino" is used to represent people of all genders who have immigrated from Latin America and/or have strong cultural ties to this region.

## Cultural Considerations:

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A 2002 study of the experience of dying in nursing homes found that lack of attention to cultural needs, when present, was a predominant factor in a person's experience of dying.<sup>7</sup> Cultural values such as the importance family loyalty (familismo), traditional gender roles (machismo and marianismo), and respect for authority (respeto) will impact how Latino patients and families understand and negotiate complex disease.

Palliative medicine is uniquely positioned to minister to the cultural needs of a family.<sup>8</sup> Research suggests that increased involvement/proximity with families improves cultural barriers, providing evidence again for more routine and earlier involvement of palliative care.<sup>9</sup> Once involved, providers should demonstrate interest in a patient's heritage and culture, striving for family-centered care that respects differences when present. Though there are cultural archetypes discussed above, ultimately every family has a different background of experiences that they bring to the table. At a system level, there is a need to provide better education on culturally competent care in medical education. Indeed, the Institute of Medicine has published two reports underlining the necessity for cross-cultural training in medical education.<sup>10,11</sup>



## Practical Considerations:

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Latino families are at significant risk for financial instability, especially so amongst Latino patients seeking palliative care. High healthcare utilization depletes financial resources for frequent out-of-pocket expenditures. Often one caregiver must stay at home to care for a complex child, impacting overall family earnings. Parents who are able to work need frequent time off to take their child to appointments or hospitalizations.

At a system level, there is a need for advocacy for improved social safety nets and support for children with special health care needs and their families. At a bedside level, the greater prevalence of financial hardship amongst children with special health care needs suggests that multidisciplinary palliative care teams should more regularly incorporate social workers, case managers, and care coordinators to help minister to these hardships. Enhanced care coordination support, respite care, and direct home care could help mitigate economic burdens and other practical/financial needs. Given that Latino caregivers are disproportionately at risk for financial barriers, palliative care providers should be more intentional in inquiring about practical limitations to care. Palliative medicine providers are afforded a more intimate relationship with families than are other doctors, such that those families may be more willing to divulge these circumstances.

## Language Considerations:

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About 37 million people in the United States speak Spanish at home, around one-fourth of whom do not speak basic English. Complex communication in palliative care is particularly vulnerable to a language barrier, and as many as half of palliative care providers have noted a language barrier to regularly affect care.<sup>12</sup>

National Standards for Culturally and Linguistically Appropriate Services (CLAS) make clear that trained interpreters should be available for all individuals with limited English proficiency at no cost. It further discourages the use of untrained interpreters or family members. It is incumbent on palliative care providers to adhere to these recommendations in order to better serve their non-English speaking families, especially given the complexity of many palliative medicine conversations.

At many institutions, bilingual care coordinators are used effectively to help families negotiate other institutions (e.g., pharmacies, DME companies, etc.) who utilize Spanish communication less well. Having bilingual care coordinators as a point-of-contact for Spanish-speaking caregivers may help reduce the psychological barrier introduced by the language barrier, and these relationships can be quite close and important for these families.

## Poor Access and/or Utilization of Palliative Care:

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Latino individuals are well known to underutilize palliative care and hospice relative to Caucasians. Latinos are also less likely to complete advance directives and, when completed, more likely to request aggressive medical interventions regardless of clinical circumstance.

As is true throughout the field, it is likely that underutilization of palliative care is in part due to poor understanding of the services it affords. There is a need for more wide-spread education about palliative care amongst providers, who can then help to dispel myths about palliative care amongst patients. Palliative care, once

provided, should always be patient-centered and rooted in family values. All efforts should be made to ensure patients and caregivers that the goal of palliative care is not to facilitate the end-of-life, but rather to match the care provided to patient and family values. Earlier referral to palliative care can be helpful to dissociate palliative care from end-of-life care. Caregiver distrust can be mitigated through longitudinal relationship.

At a system level, undocumented immigrants would benefit from opportunities to obtain medical insurance, especially so in the setting of severe illness or end-of-life. Families should be made aware of the possibility for charity palliative care or hospice care when available. Some undocumented caregivers may fear seeking help due to concerns for deportation, and there should be reassurance against this ulterior motive.

## Considerations at the End of Life:

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Early palliative care is essential in ensuring that a family's values are explored as the end-of-life approaches. As there is evidence that many Latinos prefer to die at home, families should be made aware of the availability of home hospice care for their children. Given the evidence that Latino patients are more likely to have uncontrolled symptoms at the end of life, palliative medicine providers should remain vigilant in assessing and managing symptoms that may otherwise go uncontrolled.

Following death, providers should strive to provide continuity in caring for the family in the bereavement as well. Incorporation of spiritual care is vital for the many families who endorse religion. For neonates, baptism should be offered when consistent with family wishes and available. For patients dying in the hospital, liberalization of visitation restrictions may be especially important given the importance of the nuclear family in supporting bereaved parents.

## Conclusion

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There is an appropriate recognition in palliative medicine that disease occurs not in a vacuum but in the context of a broader familial, cultural, and societal picture. Providers should be aware of the impact of ethnicity on a patient's perception of disease/death and the family's experience with the health care system. As demonstrated, Latino children with special health care needs, especially at the end of life, are at risk for more fragmented care and negative outcomes. It is vital for the palliative care physician to understand the nuances that may be present in the care of Latino children in these circumstances in order to help mitigate that disparity. There is a similar, equally important obligation to understand that people will differ even within the same culture. Though an awareness of commonalities is important, it is first and foremost incumbent on the palliative care provider to seek to understand family values with curiosity and humility, regardless of ethnicity or circumstance.

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# How One State is Working Towards Equitable Access to Pediatric Palliative Care in the Community

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The Children's Hospice and Palliative Care Coalition of California (CHPCC) has a long history, starting in 2001. From 2001–2015, CHPCC was an independent, child-focused organization that facilitated groundbreaking legislation in the state of California to improve access to community-based services. Between 2015 and 2020, CHPCC was a program under the Coalition for Compassionate Care of California (CCCC). In 2019, the Board of Directors for CCCC decided that having a pediatric coalition under its umbrella was no longer feasible. There were many reasons, one that many of us working towards increased access can relate to—financial burden. Once this decision was made, CHPCC worked with CCCC to once again become an independent organization allowing the pediatric community of stakeholders to re-form a coalition to focus on the unique needs of seriously-ill children in California. This article focuses on our work since 2020 in reigniting the Children's Hospice and Palliative Care Coalition of California with the goal of increasing access to community-based needed services for all seriously ill children and their families who would benefit from the support of pediatric palliative care (PPC) services.

Our mission at CHPCC is represented by the acronym **C. A. R. E.** To this end we undertook an initial project to identify the PPC resources in our state to facilitate access to care for seriously-ill children and their families. Our mission:

## Together We Can:

**Communicate** a common vision of quality pediatric hospice and palliative care in California

**Advocate** for public policies to serve the needs of seriously-ill children and their families

**Realize** access to quality hospice and palliative care for all children in all areas of our state

**Educate** the public and policy makers about the needs of children living with serious illness and their families

Starting with a small group of volunteers, CHPCC continued work initially started by the Northern California Collaborative for Pediatric Palliative Care (NCCPPC), taking a regional survey to determine PPC services statewide. The objective was to identify gaps in services and to provide a tool to facilitate referrals for both providers and families. The survey was initially sent out between 2016 through 2018 by NCCPPC. Thanks to a grant by the Lucille Packard Foundation for Children's Health, a project manager was hired and CHPCC was able to send out the survey statewide in early 2021. Our environmental scan of the current hospital- and community-based PPC providers and other aligned organizations throughout all of California's 58 counties was then compared to the California Department of Health and Human Services Annual Report for Hospice and Home Health. Organizations that had listed providing services to children who had not responded to the survey were called by phone to determine their status in providing pediatric palliative care services. Comparison analysis was completed, and any questions were addressed by direct phone calls to the organization/agency in question.

Data were then integrated into an environmental map, utilizing Google Maps® and posted on our website ([here](#)). Headings included all identified organizations/agencies that provided PPC services: Home Health, Hospice, Palliative Care, and Supportive Organizations. The map is searchable by geographic area and type of organization. Both inpatient and community-based organizations are listed, with their locations identified on the map. Each organization/agency listing includes contact information, service area, and services provided. Additionally, a separate downloadable database by county is also available. We trialed our map of resources for three months, inviting our Transitional Task Force and subscribers to test the map and provide feedback. We had 182 individuals access the map during this pilot phase with overwhelmingly positive results. Note: one limitation was we were unable to determine if these were 182 separate individuals or repeated visits by some.

Concurrently, while this work was being done a Transitional Task Force (TTF) of stakeholders was created. Potential members submitted applications noting their credentials, interest in PPC and experience. Members were chosen representing the interdisciplinary team including parents, as well as representing the main geographical areas of California representing both inpatient and outpatient/community-based services. The goal of the taskforce was to help determine next steps in building a sustainable coalition for PPC in California. Members shared their ideas and interviewed over 59 leaders from diverse organizations in the PPC space including 28 state coalitions; providing additional information to help guide our decision-making towards our goal of becoming a sustainable, not-for-profit organization. Additionally, we held several stakeholder calls with anyone interested in PPC invited to participate, to share our work, ask for feedback, and suggestions.

The invitation to participate in stakeholder meetings was broadcast to over 600 contacts. We do not have information on the number of parents of children with medical complexity who participated in the meetings, but developing a better understanding of this will be a goal for the future. We averaged approximately 200 participants per stakeholder call.

Parent voices were integral to the project as parent and family perspectives must continue to inform the work of the coalition and the understanding of the impact of pediatric hospice and palliative care on seriously-ill children and their families. In this phase of our project parent voices were critical in ensuring that the coalition is formed and positioned correctly to be truly impactful.

As such, parents were recruited to be part of both the steering committee and the TTF. Two of the seven members of the steering committee, three of the thirteen members of the TTF, and the project manager are all parents of children with medical complexity. Some of the parents on both committees also have professional expertise in pediatric palliative care. Additionally, two of the members of the TTF and one of the steering committee members are bereaved parents.

## Lessons Learned

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In interviews and meetings with stakeholders, a number of key priorities for our statewide PPC Coalition were identified: (1) to engage participation from diverse stakeholders and foster connection amongst the extended PPC community; (2) to provide/expand PPC education and awareness for providers, parents, and legislators; (3) to improve reimbursement for PPC services which includes revising existing PPC legislation; and (4) to increase access to adequate, equitable community-based PPC services throughout the state.

Additionally, the environmental scan uncovered large portions of the state that lack adequate PPC services. Children from many parts of the state do not have access to any of the PPC services examined, which included hospital-based programs, community-based hospice, and home health agencies providing pediatric hospice and/or palliative care and aligned supportive care organizations. Currently, only three regions in the state have strong community-based resources for children with serious illness and their families: the Los Angeles area, the San Diego area, and the Central Valley region of California. One large urban area, the San Francisco Bay area, has limited community-based resources.

By interviewing other statewide PPC coalitions from across the country, we gathered knowledge of these organizations' structures and priorities. This helped inform the TTF of various potential non-profit structures, and key considerations in choosing a structure. These considerations included staffing, expenses, volunteer commitments, and sustainable funding streams. This careful evaluation led to the group feeling extremely confident in moving forward with a fiscal sponsor for the immediate future.

Finally, another key lesson learned was the importance of having dedicated, funded program staff who could reliably support coalition-building progress in a timely manner, instead of relying solely on volunteers. The value of this dedicated staff time has made its continuation a high priority moving forward into the next phases of our efforts.

Our work underscored the need to develop community, share resources, discuss common problems, and identify areas of need. The response to our call for membership on the TTF and for participation on stakeholder calls demonstrates the state-wide commitment to this work.

PPC research continues to demonstrate that the early integration of PPC services for seriously-ill children and their families results in better pain and symptom management, quality of life, and family and provider satisfaction. However, there is not a good understanding of the number of children in California who would benefit from PPC services and where these children live. Understanding the number and location of children would be helpful in future advocacy and infrastructure development efforts.

As a coalition we continue to represent California as an active participant in national PPC collaborative efforts. These activities include participation in a national organization of leaders of state PPC coalitions from across the country, and active membership in the national PPC Task Force. With our partners, the Pediatric Palliative Care Coalition of Pennsylvania, and the Greater Illinois Pediatric Palliative Care Coalition, we host the PPC Webinar series once per month, 10-11 months out of the year.

Insights discovered through the environmental scan, and lessons learned through re-engaging PPC stakeholders in this project continue to reinforce our goal to create a sustainable California coalition for PPC that will focus on education and advocacy to improve access to services for all children with serious illness in the state of California. We have a strong history of providing PPC services in our state. Continuing to reestablish a coalition is an urgent need for California's PPC community.

1. For more information on the history of the Children's Hospice and Palliative Care Coalition of California please visit our website: [www.chpcc.org](http://www.chpcc.org)
2. Our definition of palliative care encompasses: anticipatory guidance and support; pain and symptom management; end-of-life care in the location of choice; and bereavement support. Palliative care is the umbrella from the time of diagnosis of a serious illness through bereavement encompassing hospice.
3. The authors would like to thank the Lucille Packard Foundation for Children's Health for funding this project.

## Items of Interest!

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1. **The Pediatric Palliative Care Coalition of Pennsylvania**, the Greater Illinois Pediatric Palliative Care Coalition, and the Funeral Service Foundation have created a community resource to guide families through the funeral/memorialization planning process:

### **When a Child Dies: Planning Acts of Love & Legacy**

This resource is available in both English and Spanish and is FREE, thanks to generous funding from the Funeral Service Foundation. You pay only a nominal shipping fee. More information can be found at [When A Child Dies](#).

2. **Pediatric Go Wish Together:** A conversation game for parents and pediatric caregivers; developed by Meghan Potthoff, Ph.D., APRN-NP, PPCNP-BC, CPNP-AC in collaboration with Coda Alliance. This game is "developed to help parents navigate the unimaginable journey of their child's illness." "It is a tool that provides parents and providers a way to think and talk about what's most important to the child". More information can be found at [Pediatric Go Wish Together](#)
3. **Have you heard of the new organization PallCHASE: Palliative Care in Humanitarian Aid Situations and Emergencies?** Their primary ambition is the relief of suffering, and their purpose "To work in partnership through a visible and effective network to advocate for palliative care integration in humanitarian situations or emergencies...". Please visit their website for more information, healthcare professional training and resources in a variety of languages! [Check out their website!](#)
4. **Another great new group is the Child Life in Hospice and Palliative Care Network**, which provides child life specialists working in hospice or palliative care access to resources, education, research, and networking opportunities to establish and provide best practice care for patients and families experiencing a serious illness. They are requesting that interested members fill out a brief survey, [sign up today at CLHPN](#).
5. **A Toolkit of Autism, Grief, and Loss Resources by Hospice Foundation of America**  
The toolkit will include a variety of materials and resources, such as:
  - • suggestions for responding to the grief experiences of autistic adults;
  - • ways to provide for choice and inclusion in rituals;
  - • tips for communicating the news of death;
  - • social stories on grief for adults;
  - • videos about grief, including interview clips with autistic adults and their families;
  - • two complimentary continuing education (CE) programs for professionals; and much more!
  - • [Review Hospice Foundation of America's website to learn more.](#)
6. **A resource for pregnancy or infant loss is Share: Pregnancy & Infant Loss Support.** Share was started in 1977 in response to the urging of one bereaved family by Sr. Jean Marie Lamb, OSF. Initially providing support groups, now they offer online support groups, education, support for families and caregivers. For more information [review Share's website](#).
7. **Subjects and Contributors for Future Issues of This E-Journal**

Our future issues will be focused on the following topics. If you have any thoughts about these or any other



topics, contributors, or future issues, please get in touch with Christy at [Christy.Torkildson@gcu.edu](mailto:Christy.Torkildson@gcu.edu) or Suzanne Toce at [tocess@gmail.com](mailto:tocess@gmail.com).

#### Issue Topics: 2023 (Note: Subject to Change at Work Group's Discretion)

- Issue #70: Perinatal/Neonatal, submissions due 12/2022; Publication February 2023
- Issue #71: Standards, submissions due 02/2023; Publication May 2023
- \*Issue #72: Workforce: Different Paradigms in Pediatric Palliative and Hospice Care
- \*Issue #73: Education and Training; Barriers to, what is difficult to overcome in PPC

## PREVIOUS Items of Interest:

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### 8. NHPCO Palliative Care Online Resources:

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

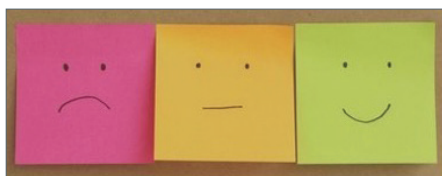
Founded in 1978, National Hospice and Palliative Care Organization (NHPCO) is the world's largest and most innovative national membership organization devoted exclusively to promoting access to hospice and palliative care and to maintaining quality care for persons facing the end of life and their families.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

- Individual Palliative Care Membership
- Palliative Care Group Application - Save by registering your entire team

9. **The Pediatric Palliative Care Coalition of Pennsylvania (PPCC)** has made a new resource available – a Sibling Grief and Bereavement Toolkit. This Toolkit has been developed to address the needs and concerns of children and teens who have experienced the death of their sibling with medical complexities. *Please see the associated article in this edition!* Below is a link to the toolkit and one of the activities – “Make a Feelings Chart”. [Click Here](#) to view the PPCC Sibling Grief and Bereavement Toolkit.

#### Toolkit Activity

For children who are grieving the loss of their siblings, returning to school can be a difficult transition. Check out this month's highlighted activity from the toolkit that may help children and teens in the upcoming school year.



Make a Feelings Chart by [downloading](#) the activity. PPCC invites you to share this information with parents, caregivers, medical professionals, providers, therapists, etc.

## 10. 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](http://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*
- 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*.

## 11. 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.

Please note the archived issues are available as a community-service by NHPCO and can be found at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics) or by reaching out to [Pediatrics@nhpco.org](mailto:Pediatrics@nhpco.org).



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