Issue Topic: Bereavement and Care, Part Two

Welcome to the 43rd issue of the ChiPPS E-Journal. This issue of our E-Journal offers a collection of articles that explore selected issues in bereavement and care. These articles offer suggestions for and examples of engaging in the important work of this aspect of providing pediatric palliative/hospice care. Because this is a huge and very important subject, we have chosen to devote two issues to these discussions. This is the second of those two issues. Even so, we appreciate that no two issues or collections of articles will do justice to this very broad subject area, but we hope that the articles in this issue and in the one that follows it will spur increased awareness and discussion, along with improved implementation or expansion of programs and interventions in this field as a cooperative enterprise with children, adolescents, their family members, the professionals, the volunteers, and the organizations involved in their care. We welcome communications from anyone who has more to offer on these subjects.

This E-Journal is produced by ChiPPS (the Children’s Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO’s E-Journal Work Group, chaired by Christy Torkildson. Archived issues of this publication are available at www.nhpco.org/pediatrics.

Comments about the activities of ChiPPS, its E-Journal Work Group, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. Please contact Christy at christytork@gmail.com.

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Issue #42: Bereavement and Care, Part Two

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

Take a Breath for Me
and
Inside This Box
Scott Newport
We begin this issue with a poem by our “resident poet” addressed to the father of a child with a life-threatening condition and an essay written later after the child died.

To My Child’s Dear Care Team
Dannell Shu
Without detracting at all from the hard work of the professionals who provided care to this mother and her child, here she shares 10 ideas in hopes of improving improve their practice.

What No One Tells You about Terminal Cancer
Caroline Collins
This essay, by a teenage girl, reflects on the illness and death of her lifelong friend, and what it all means to her.

Sibling Grief
Diane Snyder Cowan
While acknowledging the uniqueness of each sibling relationship, this article identifies some of common emotions when a brother or sister dies, notes examples of potential opportunities for growth, and suggests helpful ideas for parents and counselors.

Sheboygan Family Opens Home to Hospice Kids
Leah R. Ulatowski
Reprinted from a local newspaper, the Sheboygan Press Media, this article describes a family that has opened their home to “hospice babies” with a life-limiting diagnosis.

Supporting Children Experiencing Grief and Loss
Jennifer Mangers, MS, CLS, CIMI
This article describes the grief that children facing the end of their lives may experience over loss of a future, loss of control, and loss of attention. The article also offers ways to process such grief through legacy projects.

Two Ways of Providing Grief Support in Schools
Susan M. McIver, MDiv
In this article, the author describes how one hospice provides training to school staff along with direct support to children and teens in the school setting and beyond.

Embedding Standardized Bereavement Care for All Hospital Deaths
Marie A. Walter MS, RN, C-EFM, CPLC, and Rana Limbo PhD, RN, CPLC, FAAN
The authors describe how the Resolve Through Sharing program at Gundersen Health System in Wisconsin has developed a hospital-wide bereavement care program. Their detailed example shows how others might develop a similar program.

Inoperable
Amelia Ryan, BA, CCLS
Another source of grief and mourning is the stress often encountered in working with children who have life-threatening or life-limiting conditions and with members of their families. This article reflects on such work.

The Unfolding Journey of Grief Work
Chris Feudtner, MD, PhD, MPH, FAAP
Here an experienced pediatric palliative care physician reflects on how grief in one’s personal and professional life can intertwine, and how professionals can support each other in their ongoing work of caring for children and families when death is often the outcome.
Reader’s Corner

- Impact of a Pediatric Palliative Care Program on the Caregiver Experience
- The Indirect Effect of Positive Parenting on the Relationship between Parent and Sibling Bereavement Outcomes after the Death of a Child
- Psychological Well-Being and Family Environment of Siblings of Children with Life-threatening Illness

Suzanne S. Toce, MD
In the Reader’s Corner section of this issue, Dr. Toce offers short summaries of three articles and explains why/how they are particularly relevant to caregivers, parents, and siblings who are involved in pediatric palliative care.

Items of Interest

In each issue of our ChiPPS e-newsletter, we offer additional items of interest. If there is something you might like to share, please e-mail Christy Torkildson at christytork@gmail.com for consideration.

ADDITIONAL NOTES

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.

Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its E-Journal Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work.

If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to CHIPPS2@NHPCO.org requesting to be added to our mailing list. If you are a member of NHPCO, you can go to the Communications Preferences tab in your individual member record online and “opt-in” for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460.

Visit the ChiPPS Web page at www.nhpco.org/pediatrics for previous issues of this E-Journal, additional materials, and other resources of interest.
TAKE A BREATH FOR ME
(For my friend Pierre)

Scott Newport
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If only I could sail again
on the deep blue soul of
Lake Huron (Just off my hometown of Tawas)
I would; my main sail and jib perfectly trimmed

I would listen to the soothing breath
of the off shore breeze, eyes closed and ready to doze off
or remember the lighting bugs
wisp by my childhood dreams like tiny, slow bending shooting stars

With AuSable point on the horizon and waves gently kissing against her bow
I would feel like home was close
the sight is a favorite, familiar landmark off the leeward
like when we skimmed on the thirty footer in the Port Huron to Mackinaw race

Today I sail on a different sort of blue
from the hospital helm I set my course for true north
not knowing where I’ll land
or when the next storm will come

With my rudder a bit loose
I slip into each day knowing
if it does rain I won’t smell it coming
or feel drops when it bounces off the nearby limestone window sill

I will though inhale the breath of my family
as it fill my sails harnessing the energy to creep me along
to the next port; my next mooring
where maybe, just maybe I can take a deep breath of fresh air again

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Did you ever take the time to notice that when you look directly at a box, which actually has six sides, you can only see three sides at one time?

This is a story about choosing to see all sides of a box.

When I met Pierre for the first time, he told me something I could hardly believe. Wait. Actually, after hearing hundreds of stories, I could believe it. After all, isn’t that why Cindy, a pediatric ICU nurse at C.S. Mott Children’s Hospital, had asked me to visit with this struggling dad?

Pierre was standing close to his child’s bed when I announced, “Hey, is it okay if I come in?” The room was just like the rest of the rooms on that hospital floor. Seems like I’ve been in them all at one time or another. The children are often asleep, draped with numerous hoses and wires while their lifesaving machines stand at attention, whispering back and forth about their day’s work. Even though I am just a carpenter by trade, I know from experience what it’s like to have a sick child and so I now give back by mentoring others who are just beginning the journey.

Each time I enter a hospital room, I gently slide the glass door to the right. I know from experience I’m about to hear a chapter of someone’s life and also add another page—or at times a full book—to mine. The latter was about to start unfolding that February afternoon here in Michigan.

That day, though, it was all about Pierre’s story. It was like sitting down to read a novel or maybe like listening to one of those audio books you download to your computer. I just sat back and listened.

When I am asked to speak to medical staff that cares for children with terminal illnesses, I always stress the art of “listening to the room.” I explain during the training that even though we have a well-guided agenda when we cross the threshold into someone’s life, we need to be open to other options of care. Our good intentions can often interfere with a family’s goals and dreams, upsetting them and making good communication more difficult. Pierre and his wife fit that scenario exactly.

When I cross the threshold into a new family’s life, I try to understand the hopes and dreams of each of its members. Often moms and dads hope for different things—another example of seeing just three sides of a box when there are actually six. Opening boxes in situations where kids are sick is a sacred experience. At least that’s the way I see it, especially when engaging with families who have children with terminal illnesses.

I spent many Sunday afternoons with Pierre and his wife, Amanda. The weeks they were not admitted to the PICU to visit with their two-year-old son, I called or sent them a short text. “Hope you have a favorable wind today,” my text might read. When I first met Pierre, he told me about his time on the Great Lakes and his love of sailing. I felt that was one of our connections.

During their last extended hospital stay, some of the nurses and doctors communicated well with the family, but others failed miserably. During my conversations with Pierre and Amanda, I often wondered if the folks taking care of them were “listening to the room.” I wondered if they were seeing only the obvious, three sides of the room. If you think about it, a room is really a box. There are four walls, but there are also a ceiling and a floor. On my calculator, that adds up to six.

One day I was at the hospital for another volunteering opportunity and I thought I would stop by and see Pierre. When I didn’t see the family in their room, tears started to roll down my cheeks. “I guess I’m too late,” I whispered to myself.
While walking back toward the exit of the unit, a voice peeped up behind me, “Hey, Scott.” Before I could turn around I wiped my tears to the side and finally got the courage to look up. There standing before me was Amanda with a big smile on her face. She said, “Did you come up to see us? We moved to another room. Pierre will be happy to see you.”

The weeks passed by and after each visit, I wondered again if they would ever make it home whole.

Well, the day finally came when I received the phone call. “Hey Scott, Amanda and I would like you to speak at Christian’s funeral. You know us the best.” I accepted and was honored they asked me.

At the funeral, I read a poem about sailing that I had written earlier that year for Pierre. The poem ends with:

> With my dead reckoning a bit off I will inhale the breath  
> of my wife and ill child—I pray as their faint, warm air billows my sail  
> it will harnesses the energy I need to creep along  
> to my next port, my next mooring  
> where maybe, just maybe, I can take a deep breath of fresh air again

After finishing the poem, I spoke about how all of us, at times, need a breath of fresh air from a friend to help us move along. I invited the congregation to stand up and on the count of three we all took a deep breath of fresh air for the family.

I then stepped away from the pulpit and presented Pierre and Amanda with a gift from all of us at Mott.

The gift was a memory box I made from reclaimed pantry shelves from a home built back in the early twenties. As I moved across the church stage toward the box I said, “Inside this box,” and then my lip started to quiver and I finished, “is another box.” Slowly bending down and holding back the tears I opened the box and I gently pulled out a smaller memory box made of cherry. “This box is for Christian’s little brother, Julius.”

You see, the first thing Pierre told me when I entered his room, for the first time, was that his first son, Julius, had died a couple of years back. He was only one day old when he passed.

Boxes are interesting things, especially when you look at them from all sides, from the inside, and maybe sometimes when, like I did, you find other boxes to open. From the first day I met this family, I knew their box contained a big story. But it all began with taking the time to listen to the room, look inside the box, and let the story unfold. I’d like it if you could circle back to the ideas of fresh air and their story becoming part of a chapter in your book/story/life.

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TO MY CHILD’S DEAR CARE TEAM

Dannell Shu
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To My Child's Dear Care Team,

We deeply appreciate all your help through the years as you walked with us through the initial shock of hearing that my newborn son had severe brain damage and was not expected to live long. You were there as we finally got home, made our home into a mini ICU, trying to avoid hospitalizations and long waits in the emergency dept. We have struggled with the roller coaster of fear, hope, despair, and joy. His medical fragility continues and I am amazed that he is now five years old.

I appreciate you and know you try so hard…. However, it is difficult to say everything in a short clinic visit, particularly when it comes to the really difficult issues. So here are some things I would like to share honestly with you, that I hope will enrich you and other health care providers’ practice. These are my “top ten” that if you could remember, would make all the difference.

Respectfully,
Dannell Shu

1. My child is a whole person.

He is body, mind, soul, and spirit. He is an interconnected being. He is not just a body or a single system of a body. For example, one Doctor of ours was focused on reconstructive surgery for my son's spine when he had just gotten over 4 rounds of pneumonia and was working hard to do basic things like breathing and digesting. Another Doctor at the same time, was willing to delay reconstructive hip surgery because he recognized my son's fragile health put into question if he could endure the surgery let alone the recovery process.

2. Even though you may not believe it – I know My Child Understands

Even if he doesn't look at you or talk to you, he understands what you are saying. Please be sensitive to his presence with us. Please engage him in the conversation through touch or eye contact rather than talking "over" him while you talk to me. Ask me how best to do this if you don’t know.

3. Every medical decision impacts our whole family

From a change in medication with potential serious side effects, to moving to a feeding tube, to major surgery. All of it impacts the routines, relationships, and quality of life within our home. For example, the idea for adding a "simple" continuous feeding pump to the care plan meant that my son could no longer do needed complete physical therapy program. The pump has changed the daily rhythms of our home from mealtimes to bedtimes and has decreased the ease of being out in the community.

4. It costs us a full day's effort to meet you at clinic.

The effort it takes to prepare for my son to leave the house—gathering all of the needed and back-up supplies, moving my son in/out the car, then in/out his wheelchair and into your clinic—is only the beginning. Your clinic is an unfamiliar environment for my child. His anxiety and stress levels increase each time we come/go. By the time we return home, we are both exhausted. It can take a full day before my son has re-stabilized. This is why I ask for more time with you, for you to slow down so we can have a meaningful conversation.
5. We need your participation in Care Coordination

“So what has been happening with your son?” How do I tell my son's doctor all that has happened in the last 6 weeks with the neurologist, pulmonologist, physiotherapist...

At least 80% of our routine clinic visits for my son are spent updating each doctor on what the other doctors said and recommended in their clinic visits. Would it be possible to gather the notes from other providers and take a moment to read them before we come? This would allow you and me to spend more of our clinic time on my son's current needs and less time recounting his past.

6. I am my child's expert, you are an expert in your field.
Collaborative conversation and decision making is best for my child.

As a parent, I manage everything about my child's care and development. His medical, therapeutic, educational, social/emotional, and spiritual needs. I am with him every day, up late every night, I catch his tears, feel his pain, and witness his miracles. I come to see you because you are an expert in your field.

You know things about my child's condition and its trajectory that I cannot see from my vantage point. It is helpful when we can honor each other's expertise and work together for the benefit of my child.

7. Conventional medicine is not the only tool in our toolbox.

Pharmaceuticals, surgery, orthotics—every "tool" has its limitations. The longer my child is alive, the more complex his condition, the more my child experiences these limitations. I have had to search out new ideas and creatively problem solve how to continue to bring my child the highest quality of life and the greatest comfort. When you are not open to tools outside your scope of practice, we both lose out on having a complete conversation about my child's care. We both miss out on learning something new and collaborating on what could be most helpful for my child.

8. I need help making a care plan that reflects my family's values.

Making medical decisions without first having a care plan is risky for my child. Not every option will be helpful or improve his quality of life. As a parent, it is very difficult to articulate my family's values within the context of medical decision making for my child. I need help understanding the options and how my own medical biases can be in conflict with my values. I need a trusted impartial provider who is skilled at navigating this process. Depending on the structure of my family, I may also need help in navigating these conversations with other family decision-makers in a way that promotes unity and not further conflict.

9. It is ok to say "I don't know"

It is ok to acknowledge when you are at the end of your knowledge base. I would prefer you say you don't know the answer to my questions or what lies ahead for my son. I am comfortable with uncertainty; it is a daily part of life with my child. It would be helpful if you could be comfortable as well. When you acknowledge "not knowing" my respect for you increases.

10. Allowing yourself to connect with us on a personal level helps us trust you more

A willingness to laugh, shed a tear, be present with the unanswered questions, share a relevant story from your life; these things all add depth to our relationship. I understand professionally you are taught to keep an emotional distance. I'm not so sure this can be possible when it comes to kids like my son whose fragile bodies and strong spirits can't help but challenge the status quo for all of us.
No one tells you that every time you step outside to be greeted by the sun, it will be more than just the sun just shining down on you.

In elementary school, I met a strawberry blonde named Hannah. First impression? She was a total spitfire with a constellation of freckles on her cheeks and eyes that reflected her soul – full of life. Our childhoods were bliss. We were little girls as naive as sprouts whose roots were hardly established in the garden of this world. Hannah was a 13-year-old eternal optimist, forced to grow up too fast.

Because that’s what terminal cancer does. It steals childhoods, obliterates futures, and takes away the life in a little girl’s eyes.

I embarked on the journey of our friendship unaware that I would vicariously live through a battle of life versus death and come out in the end a new person… but without the warrior beside me to tell her own tale.
One year after her original diagnosis of brain cancer, Hannah received an update of massive tumor growth – essentially, her ticket to death. And a few days later, I ventured to the hospital with not a clue of what to expect because my best friend was invincible to me. I had never heard a complaint about the treatment wreaking havoc upon her body or the side effects. My hopes were high until reality struck my preteen world that day.

The exquisite pain of wanting something unobtainable usually becomes trivial as life goes on. But what if all you wanted was another day with a beating heart, a functioning brain, or the opportunity to breathe?

Everyone who has walked through a pediatric oncology unit has a different type of understanding of what it means to be alive. Cracked doors and windows reveal children of all ages in the midst of fighting for a change in fate… sterilization masks and hair that’s long gone, but still believing in magic. Even if that magic won’t provide them with a cure.

After getting the news myself, I laid beside Hannah in that hospital bed. And through her slurred speech and tainted vision – we put together a list of her wishes that evolved into a legacy of our friendship, the beauty of life, and death. That list holds an explanation for why I wore hot pink stilettos to the funeral and why the name “Hannah” will definitely be embroidered on my wedding gown.

Inevitably a month later, Hannah died in her very own bed, in her Monmouth County home.

It’s almost three years later, her 17th birthday is right around the corner, and sometimes the realization that she’s gone still hits me as if I’m a child standing in the ocean hit by an oncoming wave. Because when your best friend dies from cancer freshman year, no one tells you how it’s going to affect the rest of your life.

No one tells you that you’re going to be numb at the wake. And you’re going to have trouble finding the words for a goodbye letter to put under her casket’s pillow for eternity.

No one tells you that chances are – you’ll sob alone in the bathroom at school on what should have been her Sweet 16. And each milestone will conjure up more tears because it’s just not fair.

No one tells you that resting sunflowers on her grave every summer isn’t the same as the old adventures throughout the summer haze of your childhoods, and passing her house on your neighborhood run will never become easier.

No one tells you that time doesn’t stop for anyone because life comes and goes by the numbers. But the meaning of time is impossible to define until you’ve realized the value of each moment.

But no one tells you that you can venture on in the face of a horrible prognosis and move forward ready to empathize with others as they face tragedies of their own.

No one tells you that no matter who you meet or where you travel in the world, you will always find a piece of your friend. Whether it’s in that pair of vaguely familiar blue eyes on a stranger at Target. Or how you get a laugh out of Nutella gelato in Europe – because she was allergic to hazelnuts.

No one tells you that if you open your heart – you will gain a new family. Her mother becomes your mother and best friends become your sisters. The teachers who once taught you academics will teach you about life and the names of people in your hometown are no longer just familiar faces. Everyone has a story.

And no one tells you that every time you step outside to be greeted by the sun, it will be more than just the sun just shining down on you.
For me, it's the personification of sunshine... the life in a little girl's eyes... it's forever and always, **my** Hannah. And not even terminal cancer ever had a shot at taking her away.

Caroline Collins

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SIBLING GRIEF

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Sibling relationships are like no other. There is a commonality that does not exist in other relationships. When a sibling dies, the loss can be overpowering. Siblings are often thought of as the “forgotten mourners.” Friends, neighbors, and other family members offer comfort and support to mom and dad, but often neglect siblings, disenfranchising their grief.

Sibling relationships are usually the longest relationships in a person’s life. Time spent with siblings in the early years is often greater than that with their parents. Siblings share a sense of genetics, of family, of belonging, and of culture. Siblings teach each other how to function and communicate with the world.

Siblings share a special bond and a special history. When a sibling dies, this history is shattered and a void is created. The future is altered. Special occasions will never be the same. Birthdays, anniversaries, and holidays are bittersweet. A sibling cannot shout across the room or pick up the phone and call her sister to tell her the “good news” or the “bad news.” And while siblings do adjust, life is different. It is forever changed.

Based on their developmental age, children will have different grief reactions. Younger children may have magical thinking. They often feel responsibility for their sibling’s death. I was so mad that Levon got all the attention that I wished him dead... It’s my fault. OR. I want to go to heaven to visit Deidre. OR. What time will Deidre be home? At the other end of the spectrum are adolescents. Teens in the midst of individuation may be moving away from their parental system. This can lead to regression and/or challenging behaviors. Adolescents often want to protect parents from any more pain and, in fact, may not exhibit any grief responses until the family routine is re-established and parents (mom particularly) are more stable.

While everyone’s grief is unique, here are some common emotions that impact siblings when a brother or sister dies:

- **Abandonment** – When a sibling dies, there are often secondary losses. In addition to the death of their sister or brother, they may feel that they have lost their parents for a period of time or permanently. While many parents are able to model healthy grief, some parents retreat into their own grief or into their work and are unable to parent. They are unable to attend to their surviving child’s grief. This can profoundly change family dynamics.

- **Increased responsibility** – When parents are unable to parent, the surviving sibling often doesn’t just feel a sense of increased responsibility, there are actually more duties in managing the household and caring for younger surviving siblings.

- **Loss of innocence** – World views are shattered. The permanence of death is revealed for the first time. There is a marked sense of maturity in children who have experienced the death of a sibling.

- **Guilt** – In addition to survivor guilt, siblings may feel that they could have done more in the care of their brother or sister. If their sibling was seriously ill, they may feel guilty that they are glad to get their parents to themselves. They may feel guilty about being happy to have their own room. If the death was sudden or due to suicide, they may feel guilt for not having recognized any signs and symptoms regardless of if there were any or not.
• **Anger and resentment** – Many siblings feel anger after the death of their brother or sister. Most of the anger is a direct result of the death and the changes that have occurred in their life at home, at school, and with their friends. Sometimes the difficulty accepting the loss makes it easier to focus on anger. It can be a way to avoid the enormity of the loss. It may be easier to focus on who is responsible in an attempt to have control over a situation that cannot be controlled. Time is needed to work through these angry feelings without allowing anger to become toxic.

• **Fear and anxiety** – Siblings often report that they are fearful of death or getting sick. This fear and worry can persist for years. The fragility of life is real. Brothers and sisters look at their own lives and wonder if they might be next. And who else might die? Will it be mom and dad? Who will care for me?

• **Reluctance** (withholding own needs) – Because they do not want to add to the burden of parents, older siblings often withhold their own needs. They allow their grief to go unnoticed. It’s almost as if they disenfranchise their own grief. Everyone’s grief needs attention.

• **Somatic symptoms** including symptoms that mimic the deceased sibling’s illness – Headaches, stomach aches, changes in eating and sleeping are usually signs of grief in younger siblings – but still need to be checked out.

Despite these intense grief reactions, positive change may also occur after the death of a sibling. Older surviving siblings can begin a period of deep self-reflection and begin to make significant life changes. For all ages, maintaining a connection with the deceased sibling often brings comfort. Siblings will often talk to their deceased brother or sister. They can sense their presence as well as their absence. They often perform rituals. A four year old wanted to step on the backyard deck and access a ladder to the sky where she could converse with her brother. An eight year old created “heaven” under a cluster of trees where she held a tea party with her deceased sister. Parents often watch these exchanges with tenderness and envy.

Other examples of growth after the death of a sibling include:

• **Increased sensitivity and awareness** - Brothers and sisters who have had a sibling die are more aware of the suffering of others. They are seemingly more mature, empathic, and insightful about what is important in their lives.

• **Inspiration and determination** – The death of sibling can be the catalyst for pursuit of a specific career. Whoever stuck with the child, whether it be a doctor, a social worker, a lawyer, a paramedic, etc. often lays the groundwork for the future.

• **Resilience** – Children are often considered resilient. They have an inner ability to adapt and overcome adversity as well as to rebuild their life after a tragedy. Resilience improves with age as siblings gain critical thinking and self-management skills. Supportive relationships are crucial and if the family is disruptive, others are needed to provide that encouragement. Culture, tradition, and mourning rituals may support the development of resilience.

Here are some helpful ideas for parents and counselors:

• **Use honesty and simplicity** when describing what happened. Children may become confused with inaccurate terms to describe dying, such as, “your sister is sleeping,” “we lost your brother today.” Use words such as “dead” and “died.” Older children may want detailed descriptions of the death event.
- **Be available to listen** when they are ready to talk. Sometimes children are not ready to talk when we are ready to listen. If so, tell them you can be available when they are ready. When listening, give your undivided attention (no calls or other interruptions).

- **Describe the feelings of grief** they might expect to have – sad, angry, guilty, scared, worried, relieved, etc. Give examples of how you have dealt with some of these feelings. Address fears by telling them what you are doing to keep them safe and healthy. If their sibling died of illness, be sure to emphasize the fact that most people recover from illnesses.

- **Demonstrate and discuss appropriate ways to express feelings.** Share your sadness and tears with your children. Children may avoid activities or conversations to prevent their family members from crying or feeling sad. Reassure them that it’s okay if you cry after they say or do something and they are not responsible for your tears. Be sure they know that crying can help them feel better.

- **Encourage involvement in memorializing activities.** If possible, include siblings in planning the funeral or memorial services. Be sure to explain what will happen during the different parts of the service. Involve children in remembering activities: collecting photos, retelling their stories, or creating a memory box with mementos of your loved one. In addition, make plans to remember the sibling on special occasions and holidays.

- **Contact the school after the death.** Direct school staff about what should be shared and your comfort level with school grief support. Prepare the child for a return to school by making a plan with the child and school to establish a safe place to be alone at school if needed. Identify a safe person the child may talk with at school. Modify academic expectations as needed.

Sibling relationships are like no other. There may be attachments or estrangements between brothers and sisters. There may deep love or simple civility. Regardless of the bond, siblings are the ties to family. Siblings know the best and the worst of each other. They were the protectors and the antagonists. They know the history and hopes for the future. They cannot be replaced but can be held lovingly in the heart and mind.

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A Sheboygan family Mark and Cori Salchert opened their heart and their home to help hospice children.

Cori Salchert, of Sheboygan, sits on a hospital bed parked in the middle of her living room, stroking the peach fuzz on top of her newly adopted son's head. 1-year-old Charlie is at ease in his mother's arms, drifting off to the hum of his ventilator and other equipment in the room.

Cori shakes her head at the surrealism of it all.

"The crazy thing is that kiddos with a lot of equipment were something that I never wanted to do," she said. "I was scared to death that I would accidentally hurt them."

In fact, while they always liked the idea, serving as foster and adoptive parents did not seem feasible for Cori and her husband, Mark, a few years ago because both were working full time. The couple also already had eight biological children.

Cori had a passion for helping families through difficult times as a registered nurse and a perinatal bereavement specialist of the Hope After Loss Organization (HALO). The organization helps families cope with the loss of a pregnancy or newborn child.

If parents were too overwhelmed with emotion to hold their baby whose pulse was waning, Cori would cradle the child so "no one had to die alone."

While her work was fulfilling, it often exposed her to what she calls "hospice babies," or infants who had a life-limiting diagnosis and whose parents had given up guardianship because of the situation.

Cori said many of these babies spend their short lives in a bassinet in the corner of a hospital, perhaps never even being held if they are tube fed and do not need to be removed from the crib.
"There was no judgment on my part that the parents should just be able to deal with the circumstances," Cori said. "But I thought, 'Wow, I would really like to take those kiddos and care for them.'"

About five years ago, Cori was struck with an autoimmune disorder that caused gastrointestinal distress and required multiple surgeries that led to further complications. The symptoms of Cori's illness left her without a job and feeling hopeless.

"My prayer at that time was asking how God could possibly use this for good," Cori said.

As fate would have it, Cori's circumstances opened up the time for her to pursue the Salcherts' dream of becoming foster parents to hospice infants. They connected with Children's Hospital of Wisconsin's treatment foster care program, which matches families with children who have significant to severe behavioral or medical challenges.

The Salcherts brought home Emmalynn in August 2012. She did not have the left or right hemispheres of her brain, only the brain stem. She lived 50 days.

Emmalynn passed away tucked into Cori's fuzzy green robe "like a kangaroo" while foster mother and daughter sat alone at the kitchen table one night.

"Emmalynn lived more in 50 days than most people do in a lifetime," Cori said.

The Salcherts' next foster child was Jayden, who was able to overcome his medical challenges to become a thriving toddler. He was ultimately adopted by a cousin of his biological parents.

With Emmalynn's passing and Jayden leaving the home, the Salcherts were heartbroken. Cori recalls turning to Mark and saying she was done with treatment foster care, but her husband encouraged her that "this is what she was meant to do."

The Salcherts believe it is important to involve children living in the home with decisions about foster care, so they rounded up the gang.

Cori asked, "Are you all ready to do this again?" She assured them it was OK if the answer was "no."
But the Salcherts were met with a resounding, "Yes." Mary Elisabeth, one of the Salcherts' daughters, even piped up, "Mom, what if some kid really needs us and you're just sitting here with a broken heart?"

They called their social worker and were matched with Charlie a week later. The family was grateful for the hospitality of the Ronald McDonald House in Milwaukee while the Salcherts began learning how to care for the baby.

Charlie has Hypoxic Ischemic Brain Encephalopathy, which means he experiences neurological impairments as a result of a lack of oxygen. He is tracheostomy, ventilator and tube feeding dependent, among other medical challenges.

The first time Cori had to start working with Charlie's tubes, she broke down sobbing over his crib in front of the nurse training her, overwhelmed with the fact that the little boy would not be able to breathe and could suffer if she hesitated or made one wrong move.

"But, God told me we're going to kick this fear in the butt," Cori said. "It's OK to be afraid, but never let fear cripple your life.'"

It did not take long for the Salchert family to make Charlie's care a part of the routine at their house. He was adopted by the family on Dec. 18.

But, while Charlie has brought the Salcherts much joy, Cori is quick to point out that the family is not perfect, and she "isn't exactly supermom."

Her children have cried when she was forced to split time between hospital visits and birthday parties because Charlie was having a rough patch. She holds up a pair of her teenage son's boots, showing how the insides are tattered and must be digging into his heel, and she only just discovered it.

Like most families, the Salcherts are still improving communication with each other about their needs every day. But overall, the happy moments always come on the heels of a setback for Charlie.
Charlie's older sisters love to climb into his bed and cuddle or watch movies. The family enjoys taking walks together in the summer and invested in a stylish pair of shades for Charlie to wear in the sun.

In addition, the Sheboygan Fire Department made Charlie an honorary fireman, and the Salcherts' church, Crossroads, is always there to support them.

Mark said Charlie “really brings out the nobler parts of a community” when others rally around him.

Adoptive mother Cori Salchert poses with Charlie Salchert, Wednesday, December 30, 2016, in Sheboygan. Leah Ulatowski/Sheboygan Press Media

Nevertheless, the Salcherts have chosen not to ignore the reality of Charlie’s life-limiting diagnosis.

“He will die; there’s no changing that,” Cori said, brushing away a tear. “But, we can make a difference in how he lives, and the difference for Charlie is that he will be loved before he dies.”

The Salcherts have clung to their faith for strength and comfort in raising Charlie and past treatment foster children.

Cori said she believes Charlie will be able to “eat without a tube in heaven, and it will be the very best food.”

The family has already spoken with funeral directors and plans to send off balloons at his future burial to “symbolize the setting free of Charlie’s soul” from the confines of his medical challenges.

When people ask Mark why his family has chosen to care for children with a life-limiting diagnosis and endure the emotions that come with such a situation, he tells them, “God is love, and He loves this little boy, and He loves us to love him. Charlie is truly an amazing individual; he’s made us richer — more alive, in a sense.”

Cori strokes Charlie’s tiny hand while cradling him in her arms.

“These children need nurses, but the overarching thing is, they need moms,” she said. “Too many people never do anything because they can’t do everything and can’t save everyone. For me, even though I can’t help every child, I’m happy to make a difference in the lives of a few.”
Treatment foster care

Amy Basting, a foster care recruitment specialist for Children’s Hospital of Wisconsin, said that while she deeply admires the Salcherts’ care for Emmalynn and Charlie, the majority of children in the hospital’s treatment foster care program do not have a life-limiting diagnosis.

“The situation where terminally ill children enter into treatment foster care is more of an exception than the norm. That is probably what makes the Salcherts so remarkable,” Basting said. “Treatment foster care often provides homes for children with a wide range of medical needs, but the majority do not have life-ending conditions.”

During the licensing process, treatment foster families can design a “profile” of the type of child they are best suited to care for.

Basting said the children in treatment foster care have significant to severe emotional, behavioral, physical or medical challenges, which differentiates them from children in general foster care.

Many healthy children in treatment foster care have behavioral or emotional needs as opposed to medical.

“The goal of treatment foster care is to support and help children with elevated needs,” Basting said.

Children’s Hospital of Wisconsin connects children with families statewide, though most referrals come from Milwaukee. Children’s Hospital of Wisconsin Community Services has approximately 131 licensed treatment foster homes in Wisconsin.

Basting said the treatment foster care program has an ongoing need for families to support the children. At any given time, there are likely “20-30 kids in need of homes.”

If families are interested in finding out more about treatment or general foster care, Basting suggests calling 414-KID-HERO or visiting Children’s Hospital’s website at chw.org/fostercare.

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Families with a seriously-ill child experience many encounters with loss and grief both before and after a child’s death. These families connect with hospice and palliative care for several reasons, but ultimately the goal is receive guidance for the transition to end of life. Child life specialists in hospice and palliative care support patients and their families with education, preparation, and memory making in an effort to decrease anxiety and enhance quality of life. They work with patients, siblings, and parents to prepare them for what to expect depending on where they are at in their journey. Whenever possible, it is ideal to utilize a Child Life Specialist who has the education and experience of working with grieving families. In those situations that it is not possible, the following encounters with a Child Life Specialist will provide basic suggestions and guidelines to effectively support a grieving child.

Grief over Loss of Future

A 16-year-old girl shared that she was sad that she would not live long enough to graduate from High School. A 14-year-old girl realized that she would never get to wear a beautiful dress for her Quinceanera. An 18-year-old boy shared that he was disappointed that he would not be there for his younger sister for her milestone events. These are just a few examples of losses that patients experience once they are aware that they will die. These children may be grieving far more things that they have not shared. However, when given the chance to discuss how they were feeling, an opportunity to provide ways to cope with these feelings of loss was created. It may be difficult to approach, but through conversations these children can be encouraged to focus on those things that they can control. After these conversations, each child was able to receive something that they didn’t think was possible. The 16-year-old girl was connected with her school and they gave her a small ceremony where she received her diploma. The 14-year-old girl and her mother were offered the suggestion to have the Quinceneara even if she wasn’t 15. She was able to have the night she had hoped for and a beautiful dress to go with it. The 18-year-old boy felt he needed to be with his sister and wrote her letters in a journal for her to read whenever she wanted some key advice from a big brother. All of these examples did not prevent the future losses, but through open communication they were able to find ways to cope with them while enhancing quality of life.

Many siblings are experiencing the loss of a future with their brother or sister. They are potentially losing their best friend, roommate, or playmate. They are watching their brother or sister lose the ability to play, talk, and walk. A 12-year-old boy explained it was difficult for him to be excited about his sporting events because his brother was no longer able to play. It is important to find ways to continue to interact even with limitations. These brothers took a stronger interest in sports on TV and were event able to go to an NBA game.

Siblings can also experience the loss of identity. A 5-year-old boy asked his dad if he would still be a brother after his sister died. This question came as a shock to the dad because in his mind his son would always be a brother. However, it brought to his attention that people may ask “do you have any brothers or sisters” and dad realized it would be a difficult question for his son to answer. They discussed that the brother would always be a brother just in a different way. They talked about ways that the boy could answer this question as simply as “yes, I had a sister but she died” or “I have a sister who is now an angel.” They also discussed the option to say he did not want to talk about it or directing them to his parents for information. Dad realized that many of the questions he was thinking himself (“Do I still have two children?”) were similar to the questions his son was having.
Grief over Loss of Control

Many children who are approaching end of their lives start to notice that their bodies are changing. They are no longer able to do things that they used to do and they require more assistance from caregivers with everyday routines. When these children begin to lose these abilities they often seek out other ways in which they can gain control over themselves. A 13-year-old boy shared that he wanted to be informed about what to expect ahead of time so that he could determine how he would handle it. It is important to educate children on what to expect so that they can begin to develop ways to cope with it. As this boy continued to decline he was able to make decisions about his nutrition and his medications so that he could control aspects of his care. This is an excellent example of how providing developmentally appropriate information can offer a child the chance to cope through use of decision making. A 15-year-old boy was often tearful when discussing the loss of his ability to walk. His 4-year-old brother would come to him daily and ask him when he would be able to play football again and each day he would have to remind him he could no longer do so. He realized that he was sad not only for the loss of playing with his brother, but also over the ability to control his own body. He felt like a failure for letting his brother down. In situations like this, it is helpful to allow the child the opportunity to have these feelings without trying to change them. They are reasonable feelings and it is important for them to be expressed. In this situation, the child discovered an alternative way that he could support his younger brother by offering to have movie time with him and take naps together. They both were able to find a way to spend time together and the patient was able to help his brother fall asleep which was a difficult task. There are usually ways to support these children by finding alternative ways to give them control and choices.

Grief over Loss of Attention

It is common to meet siblings of chronically-ill children who say they feel ignored or left out by caregivers. They often are seeing their parents or other caregivers spending a lot of time with their ill brother or sister because the ill child requires more support for feeding, daily cares, and medical needs. Although it might seem obvious that these tasks need to be accomplished, siblings often just see that they are receiving less attention. These children need to have the opportunity to spend one-on-one time with parents and have open communication to discuss how they are feeling. A 5-year-old sibling told her mom that she never spent as much time with her as she did with her sister. Mom explained that her sister needed help with being fed and having a diaper changed and that the sibling was capable of doing things independently. The sibling did not see this as a fair answer and began to ask for help with feeding at the dinner table. Mom realized that her explanation didn’t change the support that sibling was receiving. After further discussion, mom set aside 15 minutes each evening before bed to do an activity of the sibling’s choice. During these times, mom reminded the sibling that she was able to go to the movies, shopping, and to play dates in a way that her sister would never be able to do, so there would be time spent with both children in different ways. Mom found that short amounts of time every day provided the sibling with the feeling of importance that she needed. Another young boy was told that he could not play sports because mom and dad were not able to get him to practice and events. The boy was disappointed but understood his parents needed to be home with his sister. This situation is common since help isn’t always available. However, these activities are what allow the siblings to maintain their normalcy in an environment where there may be very little. It is helpful to reach out to team parents, the coaches, or members of the group or organization to see if there are ways to help these siblings still attend these events when parents cannot take them. These activities provide an outlet for the siblings and they create friendships that can continue to support them through their brother or sister’s death.

Processing Grief through Legacy Projects

Children can be supported in coping with their feelings of grief and loss through activities and projects. Every memory making or legacy project that is created has a goal of bringing families together. It is helpful to know their interests in order to offer activities that will help express themselves. A 14-year-old girl created a documentary of her bucket list that she wanted to accomplish before she died. Her parents were aware and gathered memories from friends and families to include in the documentary to surprise their daughter. The daughter had the same idea and included messages to her mom, dad, and sister at the end to let them know how she felt about them. In the end, everyone was grateful that they had the
opportunity to experience this activity together. Other children may find that a scrapbook is a way to represent themselves and their experiences. When a child has a literary side there are ways for them to write stories to pass on to family and friends. Technology has created apps on tablets and iPads that allow children to make puppet shows, movies, books, and many other pieces of material that they can work on with their siblings that offer the experience of spending time together with a creation that can be shared after a child has died. The overall goal is to find something that fits the personality of the children involved and to make it a fun experience. The act of creating these projects alone can often be a memory.

There are many ways that children will experience grief. Everyone's journey is different and unique and should be treated as such. There is no "cookie cutter" way to help a child through their own dying or the death of a brother or sister. It is imperative to remember that "when we can talk about our feelings, they become less overwhelming, less upsetting, and less scary" (Fred Rogers). The examples provided in this article discuss ways in which communication has offered the information needed to help children cope with the many different ways in which they experience grief. Above all, it is opening up and starting these conversations that can begin to lead to acceptance and healing.

References


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TWO WAYS OF PROVIDING GRIEF SUPPORT IN SCHOOLS

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Midland Care Connection is a local not-for-profit health care agency specializing in Hospice, Palliative Care, Home Health, PACE and Bereavement.

The Need:
Grieving children and teens are more prevalent in the school system than in years past, causing additional grief support services to be needed.

The Problems:
School systems lack adequately trained staff to provide grief support to students.
School systems experience a shortage of available staff to provide grief support to students.
School budgets are tight and few resources are available to hire and train additional staff.
Staff grief compounds compassion fatigue and malaise in the school setting.

How one Hospice Program is addressing these Problems:

Provide training to school staff:
In 2014, Midland Care provided in-service education to 51 school psychologists and social workers regarding the grief of children and teens. The outcomes of the presentation were:

• To offer a deeper understanding of Child and Teen Grief
• To share tools that help grieving children and teens
• To resource school staff with referral sources that can assist in this work

During the three-hour presentation, school professionals expressed the difficulty of dealing with grief in their personal and professional lives. Some expressed compassion fatigue and a general malaise when grief becomes rampant in the school setting. When a teacher or another school staff person dies, therapeutic staff grapple with their own sadness and loss—and their desire to help students cope with loss. Community resources and agencies (such as Midland Care) offer solid and objective support for school staff, administration, and students. Educational presentations provide resources to school staff and bolster their own confidence when dealing with death in the school setting.

Informally, supportive phone calls and emails, newsletters, and event information augment the training for staff. Walking alongside and resourcing school professionals is one way to provide support for those dealing with difficulties in the school setting.

Provide support for children and teens in the school setting and beyond:
In addition to resourcing school staff, Midland Care works directly with students. School grief groups/peer support groups are scheduled by school staff to fit into the daily routine, meeting the current grief needs of the students. Groups may happen during or after school, every week or every other week—for up to 8 weeks at a time. The activities for school groups vary based on the age of the griever, yet the content is relatively the same. Topics for in-school sessions include (but are not limited to):

• What is Grief?
• Acknowledging the Reality of the Death (Telling the Story and Building Connections)
• Embracing the Loss (Feelings/Day to Day Experiences)
• Remembering the Person who Died (Memories)
• Developing a New Identity (Holidays & Special Days)
• Receiving Ongoing Support (Naming our Support Systems)
• Closure

It has been helpful to include school staff in the support groups. Strong trust and connection is built through this involvement. Grants and fundraising efforts make possible this work, underwriting supplies and the time spent by staff. In 2014, seven groups were held in high schools, middle and elementary schools with 41 unique student encounters and 184 total encounters. Working together with local schools is a growth opportunity for local agencies and organizations. Such collaborations build partnerships and strengthen the community as a whole.

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EMBEDDING STANDARDIZED BEREAVEMENT CARE
FOR ALL HOSPITAL DEATHS

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Gundersen Health System’s (GHS) organization-wide bereavement care, Resolve Through Sharing®, began with perinatal bereavement in 1981 (Wilke & Limbo, 2012). Resolve Through Sharing now includes a standard of care for those who are bereaved in all hospital units and outpatient settings. Intensive education exists for staff in perinatal, neonatal and pediatrics, pediatrics and adult areas, and for the coordinators for these programs. When Diffusion of Innovation Theory (Rodgers, 2005) was introduced, we recognized its centrality in explaining the process of implementing a system-wide bereavement program and now use it as the model for our train-the-trainer workshop, Resolve Through Sharing Coordinator Training, which has been consistently updated and enhanced since it premiered in 1985.

Berwick’s (2003) summary of this theory provides insight into the process by which leaders can take elements of providing bereavement care and hard-wire the care needed across a hospital system. The theory takes into account the “… (1) perceptions of the innovation; (2) characteristics of people who adopt the innovation, or fail to do so; and (3) contextual factors, especially involving communication, incentives, leadership, and management” (Berwick, 2003, p. 1970). An embedded system includes interdisciplinary education and support, a coordinator for the entire program, unit-based experts, managerial and administrative support, and infrastructure (policies, standard operating procedures, guidelines, documentation consistency).

Historical Perspective

Over the last three decades bereavement care has advanced to become a standard of care in many areas of healthcare. Some areas such as adult hospice and palliative care have had programs available for grieving families for some time. Other areas, including perinatal, became more organized in the 1980s while other organizations continue to lack a standardized approach to bereavement care. The purpose of this paper is to provide a framework of what is needed to establish hardwired bereavement care from the time of a life-threatening diagnosis through follow-up after death.

Diffusing Bereavement Innovations

Getting Started

The reality is that patients can and will die in many different areas of a medical facility. Research has shown that death is the most anxiety producing situation that nurses face (Peters et al., 2013). Anecdotal evidence indicates the same is true for other professions. Families in diverse care units (e.g., pediatrics, emergency rooms, post-operative, gynecology) may not have any bereavement care options provided to them. These family survivors are left to navigate the grief process without the support and resources that might otherwise available in an organization with an established bereavement program. Occasionally,
isolated and individual units within a medical center may offer bereavement options or services but there is a lack of consistent information and resources offered to families and little standardization of the process.

Centralizing and disseminating bereavement care would serve to better leverage a full range of services available, minimizing overlap and enhancing consistency (Borgman, Meyer, & Fitzgerald, 2014). One way to centralize the programs offered to bereaved families is by creating the position of an organization-wide bereavement coordinator. The role of this professional (e.g., nurse, social worker, chaplain) is to coordinate and oversee the bereavement care offered throughout an institution. The key element is standardization of the care, regardless of where the death occurs. Education for all care providers can be standardized with in-service offerings, on-line education, and the RTS trainings (if the coordinator is RTS-coordinator trained). When changes in death process occur (e.g., a new regulation from the state), the bereavement coordinator can assure that all staff affected by the change will be notified and educated. Communication between staff caring for the bereaved will be enhanced with the bereavement coordinator serving as the staff liaison to the interprofessional care team at large.

Standardized bereavement care is intended for an international audience. For example, in a report from a hospital in Ireland, Walsh and colleagues (2008) noted that “…the consensus was that the coordinator was effective in raising staff awareness around bereavement issues and in developing a whole hospital commitment through training and information dissemination …” (p. 561). Some staff members continued to identify a gap in their personal knowledge of how to link available services and those needing them. Walsh and research team members interpreted the finding as pinpointing the need for standardization and centralization of bereavement program specifics (Walsh et al., 2013).

Establishing Buy-in

Currently RTS-educated professionals work on the following inpatient units: Mother and Baby Care, Labor and Delivery, Pediatric and Neonatal Intensive Care, Surgical and Digestive Care, various Medical Units, Pre-operative and Post-operative Units, Ultrasound, Respiratory Therapy, Short-stay, Emergency and Urgent Care Services, and outpatient clinics (e.g., family medicine, ob/gyn, palliative care, home care, and wherever hospice services are offered). Walsh and colleagues continued to emphasize the benefits of standardized bereavement care in this way: “Although benefits are hard to quantify, indications are that bereavement services located within the acute hospital help the grieving process, give a positive image of the hospital, and are beneficial to staff” (Walsh, et al., p. 770).

There are few if any areas of a hospital that are untouched by death. As an example, a recent RTS perinatal bereavement course included employees from Patient Admissions, Medical and Surgical, Critical Care, post-anesthesia recovery. In a 2014 white paper, Jill Wilke emphasized return on investment through patient and staff satisfaction, donations, and community reputation. Walsh and others (2013) reported that “…the process of bereavement service development was achieved without resort to professional silos; in other words, although the social work department took a lead role in service development, they were not seen to have an exclusive role” (p. 565).

A multi-hospital, outpatient, and home care healthcare organization provided RTS education to staff and coordinators on all units where grief support is needed, establishing a sustainable model for care, education, and patient and staff satisfaction. What is necessary for such a large undertaking to be successful? We identified these factors: 1) strong, on-going support from senior leaders; 2) a highly respected coordinator of the entire project; 3) project management tools and skills; 4) careful planning for coverage for those attending the training; 5) strong interprofessional model; 6) pre- and post-training evaluations with both quantitative and qualitative measures; 7) carefully arranged audiovisual support; 8) clear link for planners and attendees of the training’s link to mission and vision; and 9) single and long-term on-going meetings scheduled as part of the planning and dissemination. Finally, whether planning standardized bereavement care dissemination in a small, rural hospital or in a multi-state health care organization with tens of sites and thousands of employees, one cannot overestimate the importance of the clinical manager’s role. It is pivotal. Their buy-in virtually guarantees success; their lack of enthusiastic
support likely means a program and services that begin strong but fade over time, lacking sustained enthusiasm.

**Practical Matters**

*Organizing items for families*

Helping families create memories and making mementoes for them requires a dedicated space for this work and the supplies needed. Blankets, articles of clothing, various supplies needed for footprints and molds, and safe storage of a digital camera necessitates a room or locked cupboard at the least. This space is also perfect for storage of the patient educational material and death process forms. Keeping all bereavement materials in one location decreases staff frustration when trying to put together multiple items for a family. Additionally, a spread sheet with items listed, contact numbers for replacement, and specific ordering details allows for a supply tech or other designated staff to keep the area well stocked.

*Record keeping*

An important consideration when assuring accurate documentation is the creation of forms or standardized notes or smart phrases. This process is simplified if you are currently using an electronic health record (EHR). Most EHRs can accommodate checklists and other templates for documentation. These serve as an informal check and balance to assure items are covered. A bereavement form can consist of a series of check marks indicating the care offered and the parent responses. This example relates to autopsy: [☐Autopsy discussed  ☑Autopsy accepted  ☐Autopsy declined.] In this manner the critical elements of bereavement care will be consistently attended to, and once documented, others involved will be aware of the care provided.

**Barriers and/or Challenges**

A system-wide approach to bereavement care makes sense. The leader (bereavement coordinator) is centralized, with decentralized unit- or department-based care. Staff on each unit or in each department where someone is diagnosed with a life-threatening condition, is dying, or dies, need policies, protocols, standard operating procedures, and staff education that is specific to the population served.

Following are some barriers or challenges that Resolve Through Sharing has identified in the past 35 years that every organization implementing a system-wide program of bereavement care should consider, anticipate, and provide for.

**On-going Education**

It is erroneous to presume that if someone has had bereavement education online, in the classroom, or engaged in a blended learning approach that “once is enough.” We recommend:

1. Including care of the grieving family in annual mandatory education
2. Including care of the grieving family in annual competency assessment
3. Attending and/or presenting at a regional or national meeting once a year
4. Seeking innovative ways to remind staff of what is new in bereavement care (e.g., post a new journal article in the staff report or conference room)

**Records: Keeping all staff fully informed**

When a baby dies, the care of the baby and family typically involves several departments and numerous disciplines. With the advent and frequent usage of an electronic healthcare record (EHR), communication among those involved in the care can be easily included in certain sections of the EHR. We recommend working with your electronic record vendor to have these sections included:
1. Accessible notes between ambulatory (outpatient) and inpatient (e.g., labor and delivery, neonatal intensive care) units.
2. Clear documentation of spiritual care.
3. Checklist for care of the mother after delivery (e.g., keepsakes, decision about disposition of the baby following miscarriage, and photography).
4. Documentation of follow-up care after discharge (e.g., what topics were covered in a telephone call, any referrals made).

Case Example:

Shawn and Angel found out at their 18-week ultrasound that something was likely wrong with their baby. Their Family Medicine physician sent them to see the perinatal team for further evaluation and discussion. They met with the genetics counselor for family history gathering and to discuss potential genetic tests available to them. Another ultrasound was completed and they had a long discussion with the Maternal Fetal Medicine physician. Further testing revealed that their fifth baby, a girl named Allison, had Trisomy 18. After much consideration and meeting with a Clinical Nurse Specialist in the MFM clinic they decided to continue their pregnancy to its natural completion. They were entered into the Perinatal Palliative Care Program. Over the course of the next 16 weeks a birth plan was completed for the couple. They also met with the Neonatologist to discuss their hopes and dreams for what likely would be Allison’s brief life. They met with the Neonatologist and a detailed Neonatal Advanced Care Plan was created and placed, electronically, with the birth plan. Their main wish was to have Allison born alive and to be able to introduce her to her siblings and other family members. They wanted to spend quality time, how much ever would be possible, with their daughter. At 35 weeks Angel had spontaneous rupture of the amniotic membranes. When she presented to labor and delivery, sadly, there was no longer a fetal heartbeat. Despite this change in hoped for outcome they were able to fulfill much of the rest of their care plan for Allison. In the quiet of the labor room Allison was delivered to Angel’s chest where she cuddled and remained until the delivery was completed. Then Shawn gently bathed and clothed her before meeting her siblings and grandparents. Footprints, foot molds, and name bracelets were made and pictures were taken with family. A blessing was done by their pastor and the funeral plans and burial were finalized. Although not exactly as they planned, Allison’s birth was special and meaningful.

Summary

Embedding standardized bereavement care within an entire healthcare system requires an interprofessional team (with education and collaboration as key emphases), support at all levels of management, and a bereavement coordinator to assure standardized care regardless of where the family’s point-of-entry (Limbo & Kobler, 2016). Four key disciplines should be included in the planning and in advisory roles after implementation: nursing, social work, spiritual care, and medicine. Resolve Through Sharing’s 35-year history now includes Bereavement Training in Perinatal, Neonatal and Pediatrics, and Pediatrics and Adult Death (see http://www.gundersenhealth.org/resolve-through-sharing/bereavement-education)

In this article, we have included a framework for establishing and maintaining a bereavement program across the care continuum. We have used research, considerable clinical and consultation experience, and a successful program model to identify the framework for a sustainable program and most importantly, both practical and interpersonal elements necessary for staff engagement and family satisfaction.
References


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Inoperable. A devastating word. A life-altering word. A word that just should not exist. When some people find out where I work, they respond by saying,

“I could never work in a children’s hospital.”

They mean well, maybe, but I can’t help but feel like I’m some sort of insensitive cruel person. Because most days, I truly love my job. I am honored and constantly grateful to work with some of the best people that this world has to offer. Completely self-sacrificing, beautiful, poised, compassionate, grateful human beings. The kind that make you tear up because they are so amazingly skilled and inspiring. And fully engaged and present in some of the most difficult times a child and family will ever encounter.

In the hospital setting, you witness kids battling, overcoming, devoted parents persevering, supporting, and loving their kids wholeheartedly, you meet siblings feeling so deeply that…it’s just like no other experience sometimes. A child’s resilience, determination, and brave little spirit will knock the breath out of you. Sometimes because the little Hulks have kicked you. Spunky little fighters. They will say stuff, hard, honest, deep, trying-to-figure things out stuff that will cause your eyes to well up with this intense crazy hard-to-explain emotion. They are the best gifts that this life has to offer. Their honesty, their passion, their compassion, and their tenacity to get better inspires even the most lifeless of adults. And that’s why the good days and moments impact you in the meaningful way that they do. And that’s why the painful, horrific, sad, and challenging days impact you in the unforgettable way that they do.

There are the nights that I can’t get to my car fast enough. Twelve plus hours can be a really looooong shift. These kind of nights, I know why people say that.

“I could never work in a children’s hospital.”

Bad stuff, mind boggling awful stuff happens in this world. We all know it, in the back of our minds, but to kids? Yes. Even to kids. Sweet, innocent, dependent children. I have not found a way to callous my heart, or to restrain my thoughts from going to the deep, dark places that I have seen at work. I have safe places to cry and release the pent up tears from the day’s utter, unexplainable, inoperable sadness. In my car. At my kitchen table. On the treadmill. In the shower. In my husband’s arms.

Sometimes, all day long at work, I’m trying to balance an emotional response that shows that I truly, deeply care without completely letting myself feel the intense pain of a horrible diagnosis, a tragic accident, a child hurting. Or a mother leaving with empty arms. I don’t get the luxury of unraveling because it’s not my child. I just met him. Or her. Or them. The siblings. I tell myself, “Just do your job well. Try and relate.” No, don’t relate. Not too much. Wait, he has the same birthday as my boys. Will he even live to celebrate another birthday? Stop thinking so much. Keep it together.
In one moment, I witness a parent’s life-filled smiling eyes replaced with fear, uncertainty, and knowledge. Not the kind of knowledge that any parent wants. And I just wish I was somewhere, anywhere else, making someone a latte, or alphabetizing insurance forms.

But not tonight. I missed my exit. Again. Tears rolling down too quickly to wipe them all away. Thoughts firing at a rapidly difficult pace to keep up with. The “what ifs,” the “whys.” The pain. The hope. All of the day’s events. The sad music playing in the background. I plead with God. Through choked up breaths. I cry out. Why? Just why?

So I get it.

“I could never work in a children’s hospital.”

But, I have for 10 years. I’m not super insensitive or super human. Far from either, I think. Any strength I have is not my own. When you clock in, you have no idea what the day will bring. You open yourself up to be there for kids and families in some of their most painful, vulnerable moments. And that’s exactly what you do. You open yourself up. Fully exposed. To crying children that don’t understand what’s going on. To scared, confused parents. To a mother wailing for her dead son or daughter. You’re exposed to the fragility of life. The uncertainty. The unfathomable and incomprehensible. There is something so strangely beautiful in the midst of it all. The love woven delicately throughout the hurt. The strength amidst the unspeakable pain. The nurses, care assistants, doctors, social workers, radiology techs, interpreters, pharmacists, who I witness sacrificing their hearts to be fully present with families. To provide the best, most loving, compassionate and gentle care to people who they’ve just met. They are God’s hands. And shoulders. There, truly right there in that room, for families in some of the most painful, exhausting, and utterly horrific times of life.

You pause. You walk down the hall. Then, boom, you remember your own family. And you panic. You call home. Please answer. You hear their voices. Temporary relief. Back to it. Then, you finally clock out. Anxiously drive to get home, walk through your garage door. Get upstairs. See and feel for yourself the sleeping breathing boys. You’re reminded of the beauty of loving someone so intensely that your chest hurts thinking that you may not get home to hold them one more time.

The thing is when you open yourself up…you hurt…you feel, and you experience life through another’s eyes. And you remember those moments forever. You love more deeply. You laugh more readily. You forgive more easily. You live. You grow. And more than anything else, you walk around with this added sense. Perspective. Different from seeing or hearing or even touching. It’s an acquired sense. From your many, many experiences. There are no guarantees in life. One moment you may be helping your 93-year-old Grandma go to the bathroom. And the next, you may be sitting with an 8-year-old child who may not live to blow out 9 candles.

You’re not perfect. You’re going to get upset sometimes at the small things. Spilled drinks. Sometimes, the bigger things will get you too. But you hug your loved ones longer, tighter, more often and you make sure they always know how deeply you love them. And you try your absolute best to protect them. You have to. Because you owe it to those who you’ve met. Those who left this world too soon. Or those who didn’t get to experience relentless love. And those who didn’t know that the last time they waved goodbye or hugged their child would be that. The very last time.

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From the dog days of last summer through to the day the tulips bloomed fully in our yard, the professional and personal sides of my life blended together more than they typically do as I grappled with what would prove to be my father's fatal illness. Over those months, my dad progressed from weight loss, to the incidental discovery of metastatic renal cell cancer, to pain, to no-longer-in-pain-but-too-weak-to-stand, to a slow steady decline culminating in (as we say in the biz) a peaceful death.

Grief work: That was my task and my journey starting from that evening in the ER when I stood in the doorway of his room looking at the physician talking on the phone with the radiologists, seeing his eyes go wide and then watching him looking down and shaking his head. Nothing good follows those signs of bad news. My work continued from then until I sat at the funeral parlor, gazing up as my three children stood in front of the casket, looking down at the laid out body of their grandfather. And now it will continue for some indeterminate time, stretching forward most likely in fits and bursts, with continuing bonds both light and dark, for the rest of my life.

Both privately and professionally, our response to death is built upon what we have learned from prior losses. When I was first starting out in pediatric palliative care, someone wise in the ways of grief, Geri Haines, sat me down and in a gentle way had me stretch out my “Loss Lines”, a genealogy of whom I had loved and lost from when I was a child until that day. For me, these loss lines started with the death of my grandmother (of whom I was very fond, but recall as an eight-year old being more confused at her funeral than sad), transitioning with the death of my Uncle Frank (who was gruff and almost scary, yet now a year older than when my grandmom died, I cried my eyes out realizing — and even more so, feeling — that I would never see him again). Then came a long pause in the sequence of loss within my immediate family, but with the deaths of peers and the members of other families, until when the year after I graduated from college my Aunt Mary died from pancreatic cancer. (My lingering anger over how she was treated and abandoned by her doctors fuel part of my passion for palliative care). And then, during my pediatric residency, came the death of my sister, Beth, after a two-year journey with acute myelogenous leukemia. I will never forget how my father, when we were driving from the airport where he had picked me up to go to the hospital where Beth was in the final stage of dying what thankfully was a peaceful death, said to me: “I remember crying when I learned she had been born with Down syndrome, and now here I am 27 years later crying because she is dying,” and then choking up.

Each loss recapitulates all the preceding losses. And since loss is always painful, we try in different ways to control and contain our sorrow. In the 1960s, when grief started to emerge out of the crepe-adorned closet into which Western culture had thrust it over the preceding century, pioneering leaders like Kübler-Ross performed a great service even as they created new confines of this ineffable shape-shifting experience of grief. The response to loss does evoke myriad responses, but grief is not tidy: there are no clearly unfolding stages. Certain feelings and thoughts rise and then submerge, only to make unexpected reappearances later, following no set script. These are deep and murky processes, ones that we can feel but perhaps never fully understand. And perhaps this is because what is going on — the loss of an attachment figure, the loss of an assumptive world — is going on in parts of our brains that do not seek to understand but only to perceive and re-act. The work of grief may be within sight but out of reach of our intellect. I am sure that woven through all my experiences with death are my “implicit memories” of grief, both anticipatory and bereaved. As opposed to the explicit memories that recall to mind specific images and words and events from the past, implicit memories are the subtler but perhaps more important recollections of how things felt, the memory and reliving of feelings in the body.
For me, the felt memory of grief is, on the one hand, more passive than active, a bobbing up and down in feelings that come unbidden in waves. The term “wake” describes well what happens after someone dies, and not just the gathering of people to honor, to remember, to support. After the death of a loved one, life is disrupted as a pattern of loss spreads outward, at first so turbulent and focused, then expanding to touch more of life’s expanse, from the obvious opportunities for sadness such as the upcoming Father’s Day, to the surprising triggers such as filling a bird feeder with seed. The loss strikes one of these occurrences and reflects off in unexpected directions, overlapping with other swelling feelings until nothing is left unaffected. On the other hand, grief work for me is also active, not only in the sense of “sense making” but also in the important work of feeling what I am feeling. Being aware and accepting of my bobbing up and down awash with feelings requires intentional effort. While our intellect may not be able to sufficiently understand or control grief, we can — with the support of others — be guided by our thinking minds to allow our feeling mind to do what it does in the face of loss.

And someday soon I will be sitting with a patient, parent, sibling, grandparent, or colleague who is grieving, and all of this will be sitting there within me. I will likely feel sad for reasons I both do and do not understand, and I will try my best to be sad with them as we experience the unfolding journey of grief work.

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Impact of a Pediatric Palliative Care Program on the Caregiver Experience


Abstract: California’s pediatric palliative care program Partners for Children uses family-centered care coordination to offer hospice-like therapeutic, respite, and pain management services for children delivered concurrently with curative care and regardless of the child’s life expectancy. As an early implementer of concurrent care for children, the program provides evidence of the impact of concurrent care on children and their families. Program impact on caregivers’ perceptions of their levels of stress and worry was measured using random effect growth curve models that included survey wave, caregivers’ perceived family support, and the child’s age and disease severity. All other data were descriptive and subject to univariate analysis. Worry and stress improved in the overall study population between the baseline and follow-up surveys. Family support was predictive of reductions in stress and worry. Disease severity was predictive of stress. Family-centered care coordination is a promising tool to enhance care for children with life-threatening health conditions and reduce caregiver stress and worry. Program strategies, including individualized care planning, access to a 24/7 nurse line, and a focus on the entire family, can be a model for other states as the need for integration of pediatric palliative care for seriously ill children becomes a national public health priority.

Who is the audience for this information? Hopefully any state public health officials who are still struggling with implementation of the concurrent care provisions of the Affordable Care Act will use California’s experience as a model. The benefits of family-centered care coordination support the model of palliative care introduced soon after diagnosis. Those caring for children with medical complexity will be interested. Primary care providers for children with complex medical conditions should take note of the benefits of concurrent palliative and life prolonging care for the child and family. Caregivers should note that this model of care reduced stress and worry and seek early referral for their child.

What is special about this article? Prior to the Affordable Care Act 2010, choosing palliative care often meant deciding to forego life prolonging or disease directed care. These data from a statewide pediatric palliative care program support the benefits of family centered care coordination when used concurrently with life prolonging care. Caregiver stress and worry actually decreased as the child’s condition worsened.

Where and how can I apply this information? As the data support that pediatric palliative care provided using this program model may be even more effective for children with less severe disease, providers should refer early, prior to onset of advance disease. Public health officials in states that do not have such a comprehensive program now have data to support the benefits and should plan to integrate pediatric palliative care into the care of children with significant medical complexity as a matter of policy.

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The Indirect Effect of Positive Parenting on the Relationship between Parent and Sibling Bereavement Outcomes after the Death of a Child


Abstract:

Context. Families are referred to pediatric palliative care (PPC) programs when a child is diagnosed with a medical condition associated with less than a full life expectancy. When a child dies, PPC programs typically offer a range of bereavement interventions to these families, often focusing on parents. Currently, it is unclear which factors increase the likelihood that bereaved siblings will experience negative outcomes, limiting the development of empirically supported interventions that can be delivered in PPC programs.

Objectives. The present study explored the relationship between parents’ and surviving sibling’s mental health symptoms (i.e., post-traumatic stress disorder [PTSD], prolonged grief disorder [PGD], and depression symptoms) after a child’s death. Additionally, the extent to which parent functioning indirectly impacted sibling functioning through parenting behaviors (i.e., positive parenting and parent involvement) was also examined, with a specific focus on differences based on parent gender.

Methods. Sixty bereaved parents and siblings (aged 8e18) who enrolled in a PPC program from 2008 to 2013 completed measures of PTSD, PGD, and depression related to the loss of a child/sibling. Siblings also completed a measure of general parenting behaviors.

Results. Maternal, but not paternal, symptoms of PTSD and PGD were directly associated with sibling outcomes. Paternal symptoms were associated with sibling symptoms indirectly, through parenting behaviors (i.e., via decreasing positive parenting).

Conclusion. These results underscore the importance of examining both maternal and paternal influences after the death of a child, demonstrate differential impact of maternal vs. paternal symptoms on siblings, and stress the importance of addressing post loss symptoms from a family systems perspective.

Who is the audience for this information? With family centered care, all primary care and palliative care providers for the dying child should be invested in optimal family outcomes, including the siblings. Bereavement providers will be particularly interested and encouraged to pay attention to both mothers’ and fathers’ parenting behaviors and mental health symptoms when considering the siblings.

What is special about this article? Previous research has mostly focused on maternal symptoms after a child’s death. This article focuses on both maternal and paternal influences on parenting behavior and bereaved sibling outcomes.

Where and how can I apply this information? 50-60% of mothers, fathers, and siblings reported the death as “unexpected,” even though >80% of the deaths were associated with a medical illness. Those involved in the care of the child, siblings, and caregivers have an opportunity to improve anticipatory guidance concerning prognostic uncertainty but possibility of death.

It is important to pay attention to not only parent gender when considering the symptoms of the sibs, but also the gender of the sibling. Girls were impacted more as the paternal symptoms increased. As paternal parenting behavior impacted the influence on sibling PTSD and depression, perhaps additional reinforcement of positive parenting and involvement may improve sibling outcomes.

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READERS’ CORNER (#2)
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The Indirect Effect of Positive Parenting on the Relationship between Parent and Sibling Bereavement Outcomes after the Death of a Child
Psychological Well-Being and Family Environment of Siblings of Children with Life-threatening Illness


Abstract: Background: The psychological well-being of siblings of children with life threatening illness remains largely uncharted. Pediatric cancer research suggests that a supportive family environment may protect the psychological well-being of siblings.

Objective: We hypothesized that (1) siblings of pediatric palliative care patients would show clinical/behavioral scores that were elevated but that rates of serious psychopathology would be comparable to the general population of children their age; and (2) higher family functioning scores would be associated with lower clinical scores and higher adaptive scores for these siblings.

Methods: We conducted an observational study with families in which a patient receiving palliative care had one or more siblings between the ages of 6 and 11. Parents completed the Behavioral Assessment System for Children, Second Edition (BASC-2) to assess the siblings’ psychological well-being and the Family Assessment Device (FAD) to assess the family environment.

Results: Twenty-four parents reported data for 30 siblings. Only three siblings scored in the clinical range on a BASC-2 composite clinical scale, and 11 siblings scored in the at-risk range on one or more composite scales. Higher FAD scores predicted significantly higher externalization composite clinical scores (7.54, 95% CI: 1.12, 13.97, p < 0.05) and significantly higher behavioral composite scores (7.88, 95% CI: 1.55, 14.21, p < 0.05).

Discussion: Siblings of pediatric palliative care patients are not experiencing lower psychological well-being than the general population. The prediction that a positive family environment would be associated with higher levels of psychological health was supported.

Who is the audience for this information? All providers of care for children with medical complexity and their families will be interested in this information (or they might note that it is consistent with their experience).

What is special about this article? While the sample size is small and the questionnaires were completed by the parents and not the siblings, the data support that, especially with family support, the siblings of children with a life threatening disease or condition are functioning close to normal psychologically.

Where and how can I apply this information? Providers can use these data to reassure families that, despite attention and time focused on the ill child, siblings are resilient and will, in general, do well psychologically. This may help reduce parental stress and worry. As the data also reinforce the benefit of family support, efforts to improve family functioning such as encouraging open communication, being sensitive to the siblings’ feelings, and involving them as the ill child worsens should be addressed as a routine part of care.

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READER’S CORNER. Our Reader’s Corner columns, like those in this issue, provide brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric hospice and palliative care, but that may not be known to readers. We welcome suggestions for publications to include in our Reader’s Corner and/or summaries and comments on such articles. Please send suggestions to Christy Torkildson at christytork@gmail.com.
ITEMS OF INTEREST
In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. **NHPCO Palliative Care Online Resources:**
   A variety of pediatric hospice and palliative care resources available at nhpco.org/pediatrics. Also, more palliative care resources are available at www.nhpco.org/palliativecare, including:
   - Community-Based Palliative Care
   - Legal and Regulatory Resources
   - Webinars and Courses
   - Plus more for NHPCO members

2. **Pediatric Hospice and Palliative Care Resources:**
   - The International Children's Palliative Care Network (ICPCN) is delighted to announce the release of *A Really Practical Handbook of Children's Palliative Care for Doctors and Nurses Anywhere in the World* by Dr. Justin Amery. Learn more [here](#). Download a FREE copy [here](#).
   - NIH Resources To Help Families Navigate Pediatric Palliative Care: These materials are available on NINR's Palliative Care: Conversations Matter campaign site. Read the [press release](#).
   - Continuing Your Pregnancy When Your Baby’s Life is Expected to Be Brief: This is a beautiful video highlighting the importance of perinatal hospice.
   - The Care Coordination Program at The Children’s Institute of Pittsburgh: Located on Shady Avenue in the heart of Squirrel Hill, The Children’s Institute houses both a specialized rehabilitation hospital and an approved private school. In 2014, The Children’s Institute piloted a new program available to all children with complex medical needs throughout the 23 Western counties in Pennsylvania.
   - Resources to Help Families Navigate Pediatric Palliative Care: As part of its Palliative Care: Conversations Matter campaign, the National Institute of Nursing Research (NINR) has created new materials for families of children with serious illnesses. The newly released materials include a fact sheet, a resource card to help families find support, and a series of family stories. These materials are available on NINR's [Palliative Care: Conversations Matter campaign site](#).
   - NINR Spanish Language Brochure also Available: As part of the Palliative Care: Conversations Matter campaign, the National Institute of Nursing Research has created a new [Spanish-language campaign landing page](#).

3. **Pediatric Hospice and Palliative Care Training:**
   - Pediatric End of Life Issues: A FREE CME Activity on Advance Care Planning in Pediatrics Register at the [Partners Healthcare website](#).
   - Don’t Forget the Dads! The Important Role of Fathers in Child and Family Health: This free 1-hour webinar on Friday, May 6, 2016 at 12:00 PM (Central) hosted by the American Academy of Pediatrics (AAP) Family Partnerships Network (FPN) and Committee on Psychosocial Aspects of Child and Family Health (COPACFH) will feature 3 expert fathers, who will share a summary of the research on this topic, as well as anecdotal experiences of dads. Register [here](#).
   - Pediatric ELNEC Presented by Penn State College of Medicine, Thursday and Friday, May 19 & 20, 2016, Hershey, PA. Download the brochure; register online at pennstatehershey.org/ce.
• 5th Annual Palliative Care Conference: Bridging the Gap between Providers and Families, Presented by Children’s Hospital of Pittsburgh of UPMC, Friday, May 27, 2016, Pittsburgh, PA. For more information, please contact Lori Malazich, LCSW at lori.malazich@chp.edu.

• HospiScript’s Annual Conference, June 23-24, 2016, New Orleans, LA. This two day conference will include a pediatric-specific track, as well as general sessions. More information will be available at hospiscript.com soon.

• Community-Based Pediatric Palliative and Hospice Care, Presented by Pediatric Palliative Care Coalition, June 28, 2016, Erie, PA. Please register online at ppcc-pa.org.


• 2nd Annual Pediatric Palliative Care Coalition Conference, October 27, 2016, Pittsburgh, PA. Sarah Friebert, MD, FAAP, FAAHPM (Director of the Haslinger Family Pediatric Care Center at Akron Children’s Hospital) is the featured keynote speaker who will discuss "National Trends in Pediatric Palliative Care." More information is available at ppcc-pa.org.

• NHPCO’s Fall Conference, The Intensives - Mastering What’s Next in Patient and Family Care, October 31-November 2, 2016, Hollywood, FL. Note: The conference will include a Pediatric Intensive that will focus on community-based pediatric palliative and hospice care. Visit the NHPCO website for more information on The Intensives.

4. Journal / News Articles:

• End-of-Life Care for Adolescents and Young Adults. Little is known about end-of-life care for adolescents and young adults with cancer and how often hospice versus intensive measures is used.

• Parent-Reported Medication Errors and Adverse Events in Hospitalized Children. Adverse event surveillance does not routinely include patient or family reports. How often do parents of pediatric inpatients report concerns qualifying as medical errors? Read more here.

• Nevada’s First Outpatient Pediatric Palliative Care Clinic Opens at Children’s Specialty Center of Nevada. Families whose children are affected by life-limiting conditions have a new resource to provide better understanding and better outpatient care for their loved ones. The Pediatric Palliative Care Clinic at the Children’s Specialty Center of Nevada is groundbreaking in its efforts to assist parents in this highly specialized medical treatment, the first such program for outpatients in Nevada.

• How one mom’s extraordinary love transforms the short lives of hospice babies. TODAY shared the story of Cori Salchert who began adopting what she calls “hospice babies” — babies with life-limiting or terminal diagnoses — in 2012. A new article from the Sheboygan Press Media about this family is reprinted in this e-journal, see page 15.

• Pediatric Blood and Cancer. A special issue/supplement of Pediatric Blood Cancer focused on the pediatric standards for the psychosocial care of children with cancer. Read more at:

Subjects and Contributors for Future Issues of This E-Journal:
For upcoming 2016 E-Journal issues, we plan to address issues related to: Communicating with Children, Pain Management, and Symptom Management. If you know of good topics and/or contributors (including yourself) for these and/or other future issues of this e-journal, please do not be shy! Step right up and contact Christy Torkildson at christytork@gmail.com; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you.