

Bereavement

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Pediatric e-Journal

Pediatric Palliative and Hospice Care

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Issue Topic: Bereavement

Welcome to the 67th issue of our Pediatric e-Journal. As all readers of this e-Journal know, loss, grief, and bereavement are central topics in pediatric hospice and palliative care. Team members, both professionals and volunteers, can expect to encounter these phenomena frequently in the course of their work. Children, adolescents, and family members need to be helped to cope in healthy ways with the challenges they face when they need the services of pediatric hospice and palliative care programs. In addition, professionals and volunteers need to learn from the bereavement experiences of the children, adolescents, and family members they serve. This reciprocal flow of learning applies both when such children, adolescents, and family members are coping with life-limiting or life-threatening conditions and after the death of a young person or someone who is significant to that young person. The needs of family members do not end with the death of their child or adolescent; such needs continue as surviving family members work to cope with their losses and adapt to the new world in which they find themselves without the physical presence of the child or adolescent who died.

As the members of the NHPCO Pediatric e-Journal workgroup began to plan for an issue on bereavement, we realized that this is a very broad subject area. That realization was reinforced as contributors submitted draft articles to us. The potential scope of a discussion about bereavement clearly is quite wide-ranging. Even though this issue contains what we believe to be the largest number of articles in any previous issue, we cannot expect that a single issue will cover every possible aspect of this topic, but we can hope to stimulate discussion on at least some of its major dimensions—and perhaps also to bring to readers' attention some of its lesser-known aspects.

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

Comments about the activities of NHPCO's Pediatric Advisory Council, its e-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are currently discussing topics like supporting siblings, care in the community, and standards for the issues immediately before us. If you have any thoughts about these or any other topics, contributors, or future issues, please contact Christy Torkildson at christytork@gmail.com or Suzanne Toce at tocess@gmail.com.

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

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This article is a spin-off from a prize-winning essay (link provided) by this author. Here, the author writes: "In the months after our baby son died, I often reflected upon the compassion of the people who looked after us in the hospital during the brief hours that spanned his birth and death." She offers applause for the care she, her son, and her family received: "I am reminded of the complexity of systems that must have been in place on the day our baby was born, even though at the time, in the depths of our sorrow, we just felt it as love."

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"I wrote this email for my team last week in the wake of the loss of a special patient and in the chaos of the world, thought I'd share..." The argument here is that one can access joy even in difficult times of loss. A link is provided to pursue that thought, along with two suggestions "for starting a gratitude practice and finding joy."

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Readers of this e-Journal will be familiar with the many essays this author has contributed. In this article, he reports that, "For the last ten years or so I have been mentoring families with children with terminal illness" and reflects on his interactions with one bereaved father and the sense of being alone when one is bereaved.

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This article describes the sense of magic that is often experienced by those who participate in peer grief support groups. This magic results from "the intentional environment we create for children and families to openly express their grief," an environment that is founded on "our fundamental understanding that grief is a natural and normal response to a death in our lives." That environment is shaped by skillful listening that allows participants to describe their experiences and encourages connections made between participants.

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Jonathan Cahill, MDiv

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Alysha Lacey, LPC, ATR, FT

Coping with loss and grief are not only experiences that occur following a death; they can occur in many different ways during an advanced serious illness. This article describes a program that "provides peer support groups for family members, including the person diagnosed with the illness." The article touches on topics like: sharing the hard news; different individuals have different needs for information; allowing for choices; validating emotions; listening without interrupting; and the value of a Family Questions Jar.

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Markita L. Suttle, MD, and Kathleen L. Meert, MD

Therapeutic alliances or what might be called constructive collaborations are important in all supportive and community efforts to help individuals facing life-threatening challenges, loss, grief, and bereavement. This article argues for the importance of therapeutic alliances and stresses their special value in the fast-paced, often seemingly chaotic environment of the pediatric intensive care unit.

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Amy Porter, MD, PhD, Summer Segal, PhD, MS, LCGC, and Jori F. Bogetz, MD

Pediatric trainees, including residents and fellows, have the potential to play an important role in companioning families through loss; however, they face challenges connecting with patients with SNI (severe neurological impairment) and their families and providing grief-informed care. In response to this situation, the authors write, "In this article, we explore these challenges and provide specific recommendations for ways to more fully engage pediatric trainees in companioning children and families who are navigating ongoing loss." Strategies for teaching pediatric trainees are identified for both throughout the illness course and throughout the bereavement period, along with sample texts for condolence writing and best practices for condolence phone calls.

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Jessica Sturgeon, MT-BC, HPMT

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Lorri Sisemore

This article offers a description and examples of the work of a volunteer group of photographers who provide parents with free, memorial photos of their baby who has died. Now I Lay Me Down To Sleep teaches that, "Photographs serve as a bridge to this type of parenting as well as offer healing for years to come." To say this another way, "NILMDTS has found that families rarely regret what they did, but they often regret what they didn't do." This article describes the philosophy of NILMDTS, urges professionals to encourage family members to take as many photos as they can in these situations, explains a course that NILMDTS offers for professionals, offers suggestions for maximizing memory-making, and concludes with some testimonials and practical guidance.

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Patti Budnik, RN, BSN, CPLC, and Emilie Lamberg Jones, BSW, RN, C-EFM, CPLC

In the midst of joyful expectations that accompany most pregnancies, serious maternal or fetal diagnoses can bring about major changes. This article describes a multitude of difficult decisions that can face parents in such situations, including the possibility of terminating the pregnancy. Families in such situations need "empathetic care, knowledge of the grief process, and often advocacy on the choices and rights available to their baby for end-of-life care." The article includes: tips for caregivers, resources for both parents and professionals, and two boxes: Rights of Parents When a Baby Dies and Rights of a Baby.

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Suzanne Toce, MD, FAAP

Many Americans are unaware that: "There are over 1 million fetal deaths (miscarriage and stillbirths) yearly in the US. The most recent CDC data noted that the perinatal death rate (>20 weeks' gestation through 7 days after birth) was close to 6 per 1000 live births + fetal deaths." For those who experience such deaths, the author identifies and describes 10 desired attributes of an appropriate bereavement program. It should be: continuous; interdisciplinary; comprehensive; inclusive; inquisitive; coordinated; informed; nimble/flexible; memorable; and sustained. The article concludes: "Fetal or neonatal death is a life-changing event for parents. Appropriate bereavement support can minimize the trauma and grief. All personnel dealing with such parents should have appropriate education and training. Where perinatal death is more frequent, there should be personnel specializing in perinatal bereavement available."

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Michael J. McNeil MD

This article argues that because most studies of bereaved parents "have been performed in high-income countries (HICs) amongst [white] mothers....we may not have a full understanding of the grief and bereavement experience of fathers or how to best support them after the death of a child. Also, we recognize that with the incredible amount of diversity in cultures, grieving practices, and mourning rituals around the world, the current literature is insufficient when considering interventions in low- and middle-income countries (LMICs). Therefore, we must consider how we can better support fathers and parents who reside in LMICs. Only in this way can we truly capture the global need of grief and bereavement support for parents after the death of a child." After reviewing what is known about paternal bereavement and bereavement in LMICs, the article concludes: "More concerted efforts to be inclusive in grief and bereavement research are critical as we recognize the unique experience of parental grief and how that experience is influenced by a host of factors including the social, spiritual, cultural, and economic factors the parent faces."

"We Need Support Too": Recognising, Understanding and Supporting Men through Their Grief after the Death of a Baby**48***Kate Obst, PhD Candidate*

Writing from an Australian perspective, this article expands on the previous article's concerns about paternal bereavement. Drawing on extensive research, the article discusses: how men grieve; what factors impact men's grief; and what support men want and need. The article concludes with practice recommendations for hospitals and bereavement care.

Readers' Corner**54***Suzanne S. Toce, MD, FAAP*

In this latest version of her popular series of reviews designed to guide readers to new and important articles and books, Dr. Toce summarizes the content of a new book, *Pediatric Palliative Care: A Model for Exemplary Practice*, by Davies, Steele, and Baird. The review identifies: who should read this book; what is special about this book; where and how can the information it contains be applied; and when should one get this book (NOW!). Dr. Toce highlights her review with this comment: "I found this book more insightful and helpful than any other PPC text that I have ever read, as it not only told me what I needed to know and do but, more importantly, how I could obtain or enhance the skills to optimize patient, family, and provider outcomes."

Bereavement, a Parent's Perspective

Becky A. Benson

Elliot's mother

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With Prolonged Grief Disorder, being added to the DSM-V for the first time, replacing Persistent Complex Bereavement Disorder, bereavement has now officially become pathologized. Prolonged Grief Disorder does not take into account extenuating factors such as previous traumatic experiences, depression, or anxiety. It is merely categorized and diagnosed by the persistent yearning for the person who has died and by exhibiting at least three of the eight symptoms listed here, one year after a loved one's death.

These include:

- Feeling as though part of you has died
- A sense of disbelief about the death
- Avoidance of reminders that the person is dead
- Strong emotional pain related to the death (anger, bitterness, or sorrow)
- Difficulty moving on with your life (socializing with friends, pursuing interests, planning for the future)
- Emotional numbness
- Feeling that life is meaningless
- Extreme loneliness (feeling alone or separate from others)

But what most parents who have lost a child already know is that many if not most of these so-called symptoms are normal and exhibited broadly across groups of bereaved parents specifically, and that for many, their grief is too nuanced to fit such a diagnosis. Many parents would note that there is no timeline to their moving through or beyond their grief. It's an ongoing ebb and flow. When someone we love dies, we will likely miss them for the rest of our lives. It's natural and part of the human experience. It poses the question, that what if grief cannot be overcome? And furthermore, should it be? When it is your child that dies, it's incredibly difficult to reconcile due to the fact that it often it feels unnatural and untimely. It's no surprise that many of us feel we have lost a part of ourselves; in a very real way, we have.

Additionally, for those caring for a medically fragile or terminally-ill child, your daily routine and all aspects of care are wrapped up in your life with your child. It's not surprising that when a child dies, these parents may also feel a loss of their sense of purpose, or even their sense of self. Many parents may contend with feelings of helplessness simply because they were unable to save their child. As a parent this can lead to feelings of both guilt and shame in their perceived failure to adequately care for their child, or even sustain their life. Kindness and self-compassion play an important role in a parent's ability to move forward. At this stage accomplishing even the smallest tasks can seem overwhelming when you're already emotionally depleted. I don't know a single parent of loss who didn't find themselves to be emotionally numb at some point in their grief.

While the symptoms of grief may become harmful, such as the inability to interact with the world around you, drinking too heavily, not being able to care for yourself, or becoming completely incapacitated, and medical or mental health treatment should be sought, it's important to recognize the varying levels at which these and/or other symptoms will present for all who are grieving. Coding this natural reaction in such a generalized fashion as a sickness in order to receive a diagnosis to obtain treatment is risky considering the ramifications it presents down the line when those individuals look to work through their potential trauma, anxiety, and depression that is event related, and not otherwise broadly applicable. Additionally, it's further stigmatizing for bereaved parents who are so stigmatized in society as is.

Bereaved parents want so desperately to find a way to continue to walk in what feels for them, a world broken into two parts: the before and after. Parents desire to be able to share and talk about their child with others, much the way those who have living children continue to do. For the bereaved, their children are still very present in their thoughts. At the heart of it all, bereaved parents may feel fearful that as the world around them moves forward, it will forget about their child completely. One should not shy away from mentioning their child's name to a grieving parent. It is music to their ears. Additionally, they may struggle to move forward themselves due to the emotionally pull of feeling that it may mean they are leaving their child behind. While this is, of course, not the case, it does take time for the bereaved to rectify their presence in this new world without their loved one and adjust to living in it, still.

Support is a key factor in a grieving parent's ability to move forward. Many will express the thankfulness for the initial support they received, but may feel feelings of rejection, anger, or betrayal when those initial supports fall away. Most parents report not feeling supported after the initial wave of phone calls, cards, flowers, and casseroles ceases. Most wish the outside world didn't expect them to suddenly be OK after a prescribed yet arbitrary time, such as six or twelve months. They wish their friends and family would still check in on them and recognize this will always be a paramount event in their lives.

The experience of community has been a sustaining factor for me throughout my daughter's diagnosis, illness, and past her death. Having a connecting, supportive group of other parents who understood firsthand was a safe space for my grief. It's been ten years since my daughter's death, and it's still in this small, tight-knit group I find my solace. It's with them I can relax, let my walls down, and share my vulnerability most fully. The parents I know who have lost their child report sharing this feeling as well.

The process of mourning is not one that can be and should be rushed. It cannot be bypassed for the sake of society's comfort. It should not be suppressed or ignored. We should be actively working to create a community inclusive of grieving parents in order to support them through their grief no matter how long it lasts because after all, grief is the cost of a great love lost.

“Love as it is Manifested in Institutions”: Reflections on the Art and Science of Bereavement Care in the Neonatal Ward

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A bereaved mother reflects upon the care that inspired her to write her essay “Something Good Enough,” (Norwood 2021) which won the Lancet Wakley Essay Prize 2021 (Boyce et al., 2021; [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(21\)02690-8/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)02690-8/fulltext)).

Over time I have come to understand that these memories of our son’s birth and death were not formed by accident at all, but were crafted. They had been lovingly carved by the efforts of many, many people, some of whom we met in the hospital that day and some we never will, their part having been played long ago or far away.

In the months after our baby son died, I often reflected upon the compassion of the people who looked after us in the hospital during the brief hours that spanned his birth and death. How had they known exactly to help us through the intolerable sorrow of those hours? As the months went on, I found myself using my university library account to access scholarly journals on bereavement and neonatal death, and there I learned about the many studies undertaken to learn from the experiences of parents like me. I discovered the 500-page handbook *Pregnancy Loss and the Death of a Baby: Guidelines for Professionals* (Schott et al. 2016), created by SANDS, the principal baby loss charity in the United Kingdom where I live, and was greatly moved to find each of its care recommendations supported by references to many more such studies.

I came to understand that the excellent care we received had begun long, long before the day our son was with us. The essay I wrote for the Wakley Essay Prize set out to acknowledge the history of planning and forethought behind the care that accompanies families when a baby dies, a history I described in my essay as institutional love:

Even now, at the distance of calm reflection, I still think it was love. Not a simulation of love, but actual love as it is manifested in institutions.

The image I keep returning to, when I think of the loving choreography of this care, is that of a checklist printed on coloured paper. In the busy environment of a neonatal ward or midwife-led unit, tools like checklists are necessary to ensure procedures are followed correctly. However, mindful that checklists “inevitably emphasise what should be done at the expense of how it is done” (Schott et al. 2016: 225), SANDS recommends that checklists involved in bereavement care should be differentiated from clinical checklists by printing them on coloured paper to remind staff to use them with special care, with lists not “adhered to as directives” (ibid.), but used to inform sensitively judged conversations. For me, this idea of a checklist, printed on coloured paper to remind staff to use it with special care, epitomises the intersection of bureaucracy and love, and with it an acknowledgement that this kind

of care is rather more of an art than a science, depending as it does upon a kind of experienced and research-led improvisation in moments of compassionate interaction.

The checklist in question offers opportunities for memory making, including seeing and holding the baby, making prints of hands and feet, taking photographs, cutting a lock of hair. It includes space for additional notes, and space for each question to be asked up to two times (but no more than twice), implicitly acknowledging that parents may be unsure and may change their minds, that nuanced notes may be needed to supplement tick-boxing to ensure adequate care, and above all that "parental choice is paramount" (ibid, 225, emphasis original).

Parental choice is indeed paramount. Our experience is a case in point. I describe in my essay the precious memories my husband and I created with the support of trained healthcare professionals in the labour ward, including bathing our son and dressing him; memories we continue to hold dear, and which continue to nourish us. And there were other opportunities we declined, including staying in the hospital with our son's body through the night and into the following days, or taking his body to our home to pay our last respects; practices which can be supported and made safe, and which we were offered, but which did not feel right to us. We were also made aware that the hospital could organise a cremation on our behalf; this we also declined, preferring to arrange a funeral of our own.

I believe that parents faced with the death of baby are in desperate need of stories and memories to make up for the lack of life stories they and their child have been denied. Memory-making practices like those listed in the SANDS checklist can provide some relief in this regard, and a privately organised funeral or memorial service is another such opportunity. I remember our son's funeral as a wonderful day. On that day, the little baby nobody had known, who had been with us for barely more than an hour, was as big as any of us. It was wonderful to acknowledge that he deserved a whole day, a whole funeral all his own, hymns and readings chosen, even a eulogy I had written partly before his birth and partly after, and the family gathered together, and tears wept just for him. Experienced and research-led bereavement care—institutional love, as I think of it—recognises that every baby matters as part of a family and a community with its own traditions and beliefs, memories to make, and stories to write.

Here in the UK we are still absorbing the findings of the recent Ockenden Maternity Review (Ockenden, 2022), an independent review of maternity services at two NHS Trusts which revealed multiple systemic failures, among them failures to listen to the concerns of families during pregnancy and childbirth, and failures of empathy and transparency when babies have died. The long-lasting anguish of the families affected by these events stands as a tragic indication of how important it is for institutions to integrate compassion at a systemic level. Reading the report, I am reminded of the complexity of systems that must have been in place on the day our baby was born, even though at the time, in the depths of our sorrow, we just felt it as love.

References

Boyce, N., Palmer, J., Pinion, S., Viridi, M., & Williamson, J. 2021. 'Winner of the 2021 Wakley Prize: Something Good Enough'. *The Lancet* 398 (10318): 2220. [https://doi.org/10.1016/S0140-6736\(21\)02797-5](https://doi.org/10.1016/S0140-6736(21)02797-5).

Norwood, T. 2021. 'Something Good Enough'. *The Lancet* 398 (10318): 2305–6. [https://doi.org/10.1016/S0140-6736\(21\)02690-8](https://doi.org/10.1016/S0140-6736(21)02690-8).

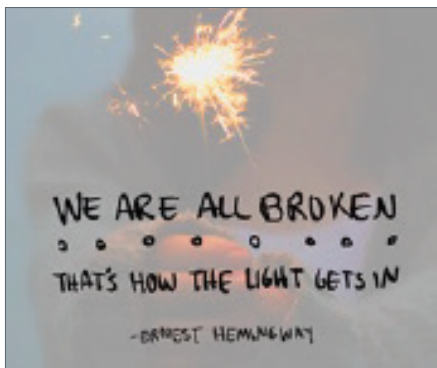
Ockenden, D. 2022. 'Independent Review of Maternity Services at Shrewsbury and Telford Hospital NHS Trust.' Retrieved from <https://www.ockendenmaternityreview.org.uk/>.

Schott, J., Henley, A. Kohner, & Hunter, A. 2016. *Pregnancy loss and the death of a baby: Guidelines for professionals*. London: Stillbirth and Neonatal Death Society (SANDS).

Kindness Matters

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Hi all... I wrote this email for my team last week in the wake of the loss of a special patient and in the chaos of the world, thought I'd share... (And, CPR stands for Compassion-Peace-Renewal)



Dear friends... a few words of reflection for the sad times, here in our halls and across the world. In our work, we hold the circle of life closer than most. We are powerful witness to the brevity and beauty of life. Some days the witnessing is too much, and our hearts break. How do we mend the brokenness? Softly, with great care, which we don't often give ourselves.

The experts say that joy can be the remedy... that joy matters, it reminds us of our humanity. But is it OK to look for joy when there is suffering all around us? Brene Brown and Karen Walrond discuss accessing joy in the difficult times in the podcast below, sharing wisdom and insight about

bringing light to the dark times. They also share some of their own practice to cultivate joy and gratitude. I hope it helps you as it did me.

<https://brenebrown.com/podcast/accessing-joy-and-finding-connection-in-the-midst-of-struggle/>

And if you don't have 30 minutes for the podcast, here are two of their suggestions for starting a gratitude practice and finding joy:

1. Take a picture on your cell phone every day for the next week of something that brings you joy... a beautiful flower, a child's smile, a furry friend, a lovely sunset
2. Journal with these three questions as a prompt each morning...How can I feel connected? (text a friend) How can I feel healthy? (drink enough water) How can I feel purposeful? (this is a slam dunk for those of us who work in pediatric oncology)

Brene Brown talks about a strong back (fierce courage), soft front (kindness), and a wild heart (love) to brave the wilderness of life. I see these things in all of you and I am so grateful

I Thought I was the Only One

By **Scott Newport**

Evan's father

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"Hey guys, can any of you feel your fingertips?" Dean asked after taking a sip of his orange juice that January morning. Dean had just scooted over and dragged a chair up for me. Over my shoulder I could see, Lisa, the waitress on her way over with my Diet Coke. My 6 a.m. stop for material at Home Depot made me late.

The men were out for a Friday, free-food thing we do every week, a breakfast paid for by the cabinet and remodeling company us sub-contractors work with. We all toss out a five-dollar bill for the tip.

There were eight of us that morning gathered around two connected tables in a local diner. Dean is the owner of the tile installation company (over 40 years, I think).

"I haven't been able to feel my fingertips for years now," he added, almost as though part of his being has been stolen by the grip of many years of hard work.

I wasn't expecting what he had asked. The grizzled carpenter next to him nodded. I nodded too but I can still feel mine, even though my hands often ache. The young guys, who we refer to as runners or laborers at the end of the table, kept on eating. The youngest was scrolling through his phone.

I guess Dean was wondering if anyone else experienced the same loss he knew. Steve, the superintendent said, "Dean, what did you say?" Steve sits at the far end with his good ear in our direction (tips of the trade).

This story is not about starting over, but sometimes I wish I could.

For the last ten years or so I have been mentoring families with children with terminal illness. This past month has been no different. I've known Bill for about the same amount of time. Recently his son's health has become unstable.

"Scott, can I run a few of the questions I want to ask the doctors past you. I respect you because I know you have been there before," Bill said.

"Well, Bill, I would first ask you what one or two of the questions that are most important, maybe three," I replied.

In a matter of minutes, Bill told me, "Scott, I have already eliminated four of them."

Sometimes I wonder if I can offer dads, like Bill, anything. I keep committing myself to letting them know they are not alone. I don't say it. I just do it.

Over the last week, Bill's life seems more desperate.

"Hey Bill, would you say you're desperate," I asked.

"What do you mean," he replied.

"I don't know," I said, "I was just wondering."

"Yea, I guess I am, but I had never thought about it like that before."

A couple of weeks ago I was asked by Michigan medicine to say a few words at the annual [Evan Newport Hope Award](#) ceremony at the University of Michigan. Yea, Evan is my son who died at the age of seven on the day after Thanksgiving in 2009. Evan spent the first ten months of his life in the I.C.U. at C.S. Mott children's hospital.

I started out by speaking of the recent victory the Michigan Wolverine football team had over longtime rival, Ohio State.

"Hope starts with grit," I said. "Out of grit, comes abundance," I added. Just think about the work the football team had to employ to successfully win. The endurance, the resilience, and belief they could win. I then talked about the hope that is realistic, not the type that is overly optimistic.

I ended with the statement, "Truth matters."

Yesterday, I talked to Bill again. The calls have become more frequent now. I listen a lot.

"Now, that I hear myself say those words, it sounds different," Bill mentioned.

"Truth matters," I said to him.

"Yes, it does," he replied.

"You're a good dad, you have taken the time to contact different hospitals for second opinions on heart/ liver transplants. And that's the truth."

He was silent for a moment; I thought he was about to cry. I continued, "Our minds can sometimes be a nasty thing."

Again, he agreed.

"Ok, Bill, I gotta go but feel free to call me anytime but just don't do it at 3 a.m. unless it's an emergency."

I could hear him snicker and we said goodbye.

This morning, I woke up to a text from Bill that started with, "God never sends you into a situation alone."

I can just see him in my thoughts on his knees praying things will turn out right.

I'm now thinking about what Dean said in so many words, "Can anyone else relate to the numbness?"

Maybe today, I should call Bill and tell him what I experienced so many years ago, not finding someone and being alone. Telling him about the numbness my heart experienced at times, mostly in the middle of those scary nights when I wasn't sure if Evan was going to make it.

I will be Praying he will maybe hear my words a bit differently and erupting from his thoughts, "I thought I was the only one."

"Bill, you're not alone." I also know what the numbness feels like.

Truth does matter even when the feeling has been stolen from us. And maybe, none of us dads with sick kids, will ever get that back. I will never be afraid to ask the question, does anyone else feel the numbness? And that's my hope, with a sprinkle of grit, hoping the abundance will someday show up one day. Even if it's not exactly what I expected, even if we can't start over again.

Grief Magic

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"I don't really know what it was, but tonight in group I just felt some of that Dougy Center 'magic' happening."

I've heard this statement many times in the five years I've coordinated peer grief support groups for children and families. It comes up most often in our "post-meeting," which is a time for Dougy Center staff and volunteers to debrief after the families leave for the night. Volunteers who talk about this "magic" usually have a distant, satisfied, almost stunned, gaze. There's a shared sense that the group time had a special quality, that the sharing and caring was, well, magical.

While I love a good fairy tale, I also know that the "magic" they're experiencing results from the intentional environment we create for children and families to openly express their grief. Creating a safe space and everything involved to make that happen is an important aspect of *The Dougy Center Model* for peer grief support. For over 40 years, the children and families we have served in peer support groups have taught us what helps them as they traverse all the changes in their lives following the illness and death of a family member.

One part of the "magic" is our fundamental understanding that grief is a natural and normal response to a death in our lives. Children and teens who are grieving want to know that how they feel, what they think or wonder about, how they act, and what they experience each day doesn't make them broken or a problem to be fixed. They want to know they're not alone in their grief, and that someone else understands what they're going through. One dad who brought his daughter to Dougy Center for their first groups wrote to us after the group: "I have to tell you that she had a fantastic time! She's asked me almost every day since we were there, 'Dad, when do we go back to Dougy Center?' On our way there, she was apprehensive, and shared with me, for the first time, she doesn't like to tell people about her Mommy because she's afraid they'll laugh. After our group, she chit-chatted the entire way home telling me about the people she met, and that lots of people had someone die in their life, and she doesn't feel scared to talk about it. Obviously, this was the reaction I'd hoped for, but I was shocked at how, in one visit, it opened the door for more conversation about her mom than I've ever heard her initiate, and it's been two years since her mom's passing."

Another part of the "magic" is the skills we use to listen and invite more conversation. In a group for young adults ages 18-24, one of the participants shared a dream they had involving their mother, and but also mentioned that their dog was in the dream. The coordinator asked about the relationship between their mother and their dog, and they smiled for the first time since joining group. The participant then talked about how their mother had a real love/hate relationship with the dog. After group, this participant emailed to say, "I wanted to say how much joy your question about my mom's and my dog's relationship has brought me. I haven't felt a lot of joy for a long time, but it truly brought the biggest smile to my face. Thank you!" Had the facilitator shifted to ask others about their dreams, or possibly reflected a different detail, that participant would have missed the opportunity to think about how their mother lived and not just that she died.

The combination of skillful listening and the perspective that grief is natural and normal creates an atmosphere where participants are willing to risk sharing their experiences. This is especially true in our groups for children and teens. When asked, "How would you explain Dougy Center to a friend," a teen group member said, "We talk about stuff. Stuff I haven't thought about. Processing different parts that I didn't know I needed to process. That's why I come to group. The activity was helpful because I started remembering little things I hadn't thought of. Remembering things about my brother....this stuff after he died and thinking back on this stuff is kinda healing I guess."

A participant in our groups for 11 to 14-year-olds described the safety she experienced being around others of a similar age who were also grieving, "I felt like if I talked in the open about this people would say 'OK, weirdo,' but everyone here is just so nice, and I can speak my mind, people understand here." Another member of the group added, "I don't really talk about my grief with my friends or anyone outside of Dougy Center...here I feel included, understood, and like people just 'get it.'" A younger participant summed it up saying, "It's like we're all one big grief family! I just love it here!"

Another important part of the "magic" is the connections made between participants. They often relate to each other through even the simplest of statements, saying things like, "I have totally felt that way before!" when listening to a peer bravely offer their experience of jealousy over the attention their sister who died still receives. This was shared during a particularly quiet virtual group, one where most of the participants had their cameras off and the screen was full of small black boxes with just names. In this situation, the "magic" was rooted in choice, another important element in *The Dougy Center Model*. Each of these participants knew they had a choice about how to engage—some by speaking and others by intently listening to one another. They don't always have the same experiences, emotions, or responses, but they respect the differences as well.

The administrator side of my role as Program Director knows the "magic" we create in our peer grief support groups is the result of intention and hard work by our staff and volunteers. But I too often feel dumbstruck at the end of a group. I sit back and feel honored to bear witness to stories shared by trusting children and teens, who may have never told anyone what they're experiencing. As one volunteer stated it, "There is something about these groups. It's so magical to see the dynamic that's created among the participants. People can talk candidly, and no one rushes in to judge, 'correct,' or disagree. Everyone is respected for their experience, even if it's different from someone else's. As one participant said, "I could have survived without Dougy Center, but with it I learned to live." For me, that's the ultimate compliment for how *The Dougy Center Model* works. How can you not call that "magical?"

For information on Dougy Center, our model of grief support, and access to our Grief Out Loud Podcast, free downloadable Tip Sheets, and many more resources, visit our website at www.dougy.org.

Guilt and Grief: A Burden Worth Exploring

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Guilt is a painful reaction frequently felt when grieving the death of a child. It arises from the dissonance between our expectations for ourselves and our sense of having failed to fulfill them (Li, Stroebe, Chan, & Chow, 2014). Guilt feeds on terrifying questions that take root in the mind like the most stubborn of weeds:

"Is it my fault my loved one got sick?"

"What if I had noticed their illness sooner?"

"Was I a bad parent/sibling/friend?"

We try to answer these questions rationally:

"Illness is natural. There's nothing I said or did that made them sick."

"I did everything I could as soon as I could. Not even the best doctors with the best medicines in the world were able to cure them."

"I didn't always know what to do, but I always acted out of love."

But even with the most well-reasoned responses, removing the pain of guilt can be difficult. Siblings, parents, providers, and friends who are left to make sense of the loss of a child can all experience guilt in their grief, and from a variety of sources. Writing on the stressors bereaved parents face, Worden and Monahan (2001) outline an extensive taxonomy of guilt.

Cultural guilt stems from the expectation that those under our care are to be protected from harm. If we cannot keep them alive, there can be a sense of not having done enough, of having failed them. Parents whose children die before them, medical practitioners whose patients die under their care, and other guardian figures who face the death of someone they are looking after are prone to carrying this burden.

Amy Amrusko, who created the blog "Callapitter" following the death of her two children, gives voice to the experience of a parent experiencing cultural guilt:

I blame myself for not being there to protect them. I realize this blame is irrational and unwarranted, however I am their mother. As far as I'm concerned, my job on this earth is to love them, take care of them and protect them from harm. And if I'm unable to protect them, I at least want to be with them when they experience bad things. And I wasn't... (2009)

Despite her acknowledgement that her feelings of self-blame are “irrational and unwarranted,” Ambrusko’s profound sense of failure arises from her own, and the broader culture’s, conception of a mother’s job as protector. The sense of having failed to live up to widely held expectations of parenthood can be devastating.

Causal guilt is when one feels responsible for the death of a loved one through real or perceived negligence, or even through the passing on of an inherited disorder. One grieving mother shared with me her pained thought that by using cannabis during pregnancy she contributed to the death of her infant son. She blamed his fatal chromosomal disorder on her use of this substance despite reassurances from her medical team that this had nothing to do with his illness. Her case shows how easily we can become our own harshest judge, even when our actions have no bearing on a loss.

Moral guilt is the sense that something we have done, which runs counter to our belief of what is right, is the cause of our loved one’s death. We perceive their death as punishment for some transgression. Worden and Monahan cite lingering turmoil following an abortion as a frequent source of moral guilt: “Because I elected to terminate a pregnancy [in the past], I am now being punished for that act by losing my child” (2001). Dennis Klass, reflecting on his years as professional advisor to the St. Louis chapter of The Compassionate Friends, notes how the search for an explanation for a child’s death may also result in moral guilt, as “fantasized, or historic faults in the family systems become enlarged in the griever’s mind” (1982). This can lead not only to further misunderstanding and estrangement among family members following the loss, but also to distorted interpretations of past events within the family. I have encountered this in the likes of the bereaved parent who blames their divorce, at least in part, for the death of their child.

Survival guilt is felt when we live on but our loved one does not. “I survived the car crash, why didn’t they?” “We both got COVID. Why am I the one still breathing?” “When my brother was sick, he got all the attention, and I used to get so jealous of him. I don’t think I was a good older brother. But now that he’s not here, I can’t make it up to him.”

Finally, there is **recovery guilt**, perhaps the most insidious of all. Klass (1982) observes that many bereaved parents think that all they have left of their child is their sadness. Furthermore, they might think that others will eventually forget about their loss, leaving the burden of being sad to them alone. If bereaved parents stop feeling this way, even for a brief time, they feel guilty for abandoning their child. Still others grieving a child’s death sometimes think that recovery dishonors the memory of the deceased. Several parents have told me that it seems “unfair” that they have the opportunity to be happy again, to resume activities that they enjoy, but their child does not. Recovery leads to self-blame, which leads to feeling trapped in an interminable cycle of guilt and grief.

Any one of these types of guilt can be unbearable. People often tell me that the sooner they can be rid of guilt, the better. But before dismissing guilt or viewing it as a strictly irrational emotion, I believe it is important to acknowledge that guilt serves a purpose. It offers an answer to the question “Why did this happen?” Guilt assumes a clear cause and effect and gives one a perception of control over what has taken place, a sense of agency, even if what occurred is horrific and its catalyst is misidentified.

There’s rarely a satisfying answer for why bad things happen, and guilt is unlikely to prove an effective coping strategy in the long run (Schroevers, Kraaij, & Garnefski, 2007). Yet in the face of a profoundly tragic event, guilt offers a way to make some sense of things. For some, finding a reason for a loss, even at the cost of misdirecting blame inward, is more tolerable than not being able to find any explanation at all. Guilt plays an important role in the grieving process, offering an island of meaning in a sea of despair.

Ultimately, however, one must venture on to safer shores. I have heard it said that shared grief is half the sorrow. Likewise, sharing reactions of guilt with others is the surest way to diminish its pain, especially when the audience

comprises others who have experienced the death of a child. In his discussion of self-help groups for the bereaved, Klass (1982) offers some important insights for breaking free of guilt. Sharing with fellow grievors helps disrupt the "conspiracy of silence" around the death of a child and reveals that many wrestle with the idea that they have failed as a parent, sibling, or friend. When stories about the child are shared, grievors also realize that others are willing to help keep their child's memory alive. The burden of carrying sadness no longer falls on one person, giving them permission to feel other reactions to their losses and helping them overcome the pitfalls of recovery guilt.

Furthermore, finding a community of fellow grievors helps "lower the perception of preventability." In other words, it helps grievors acknowledge that they did not have complete control over the events leading to their loved one's death, lessening their sense of having failed in their role as protector. Processing guilt with others facilitates unbiased analysis of the events surrounding a child's death, clarifying that often fault cannot be assigned to the griever. Even where there is fault, a person's intent can be examined, and since few actually mean to kill their loved one (though they may have thought about it), the act of public confession and reflection can lead to absolution for the guilt-stricken griever (Klass, 1982).

Guilt reactions when grieving the death of a child serve a purpose, helping one make sense of an almost incomprehensible situation. Guilt, like every reaction and response to loss, has its time and place. But it need not have the last word. Through sharing guilt with fellow grievors, one's sense of responsibility for a child's death diminishes, and the dissonance between one's expectations and one's sense of failure similarly falls away. Though the reality of the loss remains, the pain that accompanies it can be eased.

References

- Ambrusko, A. (2009, November 6). These are the dark and scary thoughts. Message posted to <https://callapitter46.blogspot.com/search?q=dark+and+scary+thoughts>.
- Klass, D. (1982). Self-help groups for the bereaved: Theory, theology, and practice. *Journal of Religion and Health*, 21(4), 307-324. <https://www.jstor.org/stable/27505701>
- Li, J., Stroebe M., Chan, C.L.W., & Chow, A.Y.M. (2014). Guilt in bereavement: A review and conceptual framework. *Death Studies*, 38(3), 381-7. <https://doi.org/10.1080/07481187.2012.738770>
- Schroevers, M., Kraaij, V., & Garnefski, N. (2007). Goal disturbance, cognitive coping strategies, and psychological adjustment to different types of stressful life event. *Personality and Individual Differences*, 43(2), 413-423. <https://doi.org/10.1016/j.paid.2006.12.009>
- Worden, J.W., & Monahan, J.R. (2001). Caring for bereaved parents. In A. Armstrong-Dailey and S. Zarbock (Eds.) *Hospice care for children: Second edition* (pp. 137-156). Oxford: Oxford University Press.

Family Pathways: Coping with an Advanced Serious Illness of a Family Member

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When someone in your family receives a life-limiting medical diagnosis, you might feel a range of responses: sad, afraid, angry, overwhelmed, confused, shocked. This news may raise concerns, questions, and anxiety about the future. When children and teens are involved, these reactions may be amplified as adults try to balance tending to their own needs with supporting their children. This mix can strain communication in the family, between individuals, and for the entire system. For 32 years, Dougy Center's support programs for families served them following the death of a family member or someone close to their family. In 2014, in recognition of the need for services when a family member has been diagnosed with an advanced serious illness, we started the *Pathways Program* which provides peer support groups for family members, including the person diagnosed with the illness. Over the years, *Pathways Program* participants have shared deep insight into what helps them when they are navigating the changes and uncertainties which accompany this new reality.

One common hurdle is figuring out how to share the hard news with a child or teen. While there will never be a perfect scenario, it is helpful to put some intention into the timing and location that will work best for the family. Use open, honest, and clear language and try to follow the cues that a child or teens gives. They may ask questions, they may be quiet, they may get angry, or they may initially need some space and return to the subject later. Some reactions are expected, while others may surprise a parent or caregiver. Eight-year-old Marcus shared, "I just came home from school and saw that my mom made me cookies. She told me that my dad had glioblastoma and I didn't really know what that meant so I just said 'OK'. Then she said it meant he was really, really sick and would be in the hospital a lot. Then I didn't really feel like eating the cookies, but I did give my dog a big hug."

Individual family members may need different information, which can also pose a challenge. In addition to thinking about a child's age and developmental level, consider their personality, needs, and way of processing as you decide what to say. Each child may need to be told differently and given more or less information based on these factors. Mari, a mother whose wife was living with advanced ALS, said "Sometimes I feel guilty because my 14-year-old daughter usually hears things right away, while my 12-year-old learns them gradually. I'm not trying to hide anything, but I know my older child does better with concepts that are concrete and thorough and asks a lot of questions while my younger child gets easily overwhelmed and needs to take things in on her own timeline." Giving children choices about how much information they receive, as well as how and when, can help them feel they have some sense of agency in a situation that feels very much out of their control.

In addition to choices, validating emotions and listening without interrupting are excellent ways to improve communication within the family. It is reassuring for people of all ages to know it's okay to feel how they feel and that they have someone to share those feelings with that will truly be present with them. When asked what adults should know about talking with their teens, 16-year-old Robert whose brother has leukemia offered, "My Uncle Joe and I have what we call 'car talks' where we just drive around together, and I can say what's on my mind. He's good at just being

quiet and listening and when I will bring up a problem, he usually says 'Well what do you want to do about that?' If I ask him what he thinks I should do, he will offer suggestions but mostly he just lets me talk it out." Bianca, 11, participated in a group activity where participants could make a card for someone in their family and write what they would like to tell them on one side and what they would like to hear from them on the other. She said, "I want to tell my mom how much she hurt me. I want to hear that she gets it, is sorry, and that she loves me as I am."

On an average day it can be difficult for family members to connect between juggling work schedules, school, homework, sports, and other extra-curricular activities, meals, and home upkeep, but when you add medical appointments, keeping extended family and friends informed, and the general lack of predictability that comes with an advanced serious illness, it can feel impossible. One solution is to create a Family Question Jar where each family member is invited to write a question and put it in the jar as needed. Roberta, whose partner has colon cancer, shared how her family uses this idea. She said, "Sometimes there are questions in there, like 'will I get cancer too?' and that showed me that it was something the kids were worried about, and we needed to talk about it with them. Other times there are comments like, 'I like when we got ice cream together today' or just 'I love you'. I sometimes try to add memories in there too to remind the kids of days where things weren't so complicated, or compliments that let them know how proud I am for enduring all of this."

One technical tip related to a Family Questions Jar: We suggest you use a clear container placed in a highly visible area, so it doesn't go unnoticed. You can also assign a child to keep a close eye on the jar and alert family members when there's something new inside or to call a family meeting.

With frequent communication, there is also more opportunity for kids or teens to ask questions where the answer is unknown. Sometimes, you can defer to medical professionals or others who are helping your family for assistance, but even then, some questions don't have clear answers. It's okay to model that adults don't always know the answer, which can sometimes feel scary and confusing. However, this normalizes these feelings and can lead to conversations about how to cope with those emotions. You may say, "When I'm nervous about something I can't control, it helps me to talk to someone and to take a long walk. What do you think helps you when you're nervous about something big?"

Finally, remember each family member is doing their best to make it through an impossibly difficult time. Communication won't always look perfect. Everybody will make mistakes as stress is high and emotions run deep. Carlos, whose wife Gloria died of breast cancer when their children were 8 and 12, spoke of the time between her diagnosis and death. He said, "I wouldn't wish it on anyone. It was hard and I felt like I never knew the right thing to say or do. I know I wasn't always well-spoken, but I just tried to be honest and remind the kids that they were loved, and we would make it through day by day. Sometimes I didn't believe it, but by telling the kids, I also kind of convinced myself. And you know what, we did make it. We all miss Gloria constantly, but I think talking through all the hard things during that time made us better at doing it now."

For more information from Dougy Center, including resources for supporting children and teens who are grieving, visit our website at www.dougy.org.

Building Therapeutic Alliances with Families at the End Of a Child's Life in the Pediatric Intensive Care Unit

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The pediatric intensive care unit (PICU) is a highly technological and fast-paced environment that can lead to high levels of stress for the families of critically-ill and/or injured children. Parents of children in the PICU often experience physical, emotional, and psychological effects both acutely and long after their child's discharge.¹ Parental stress reactions may develop from exposure to the sights and sounds inherent to the PICU environment, the uncertainty of their child's course and outcome, and the impact of the admission on their overall family function and parental role.¹ Because of the dynamic nature of the PICU, the ability of pediatric intensive care physicians to quickly form meaningful relationships with families may be hindered, potentially worsening parental uncertainty and leading to unmet family needs, especially for parents whose children are at the end of life.

The theory of Transitional Togetherness describes the dynamic nature of relationships between parents and providers in the PICU.² At first, parents may welcome the providers' expertise in caring for their child and relinquish their child's care to the providers. However, as time goes on, parents seek to become part of the caregiving team and often look to providers to help them reconstruct their parental role. After their child's death, parents gradually disengage from their child's providers over variable periods of time. Parents often appreciate contact with the PICU team during bereavement and may feel abandoned if such contact does not occur. Strong alliances between parents and providers in each of these phases allows parents to feel supported and brings comfort not only during the PICU stay but often for years to come.

Originating in psychotherapy, "therapeutic alliance" is a collaborative relationship between a patient and therapist, or in the case of pediatrics, a family and a medical provider for the purpose of treatment.³ It is a complex construct that reflects the strength and quality of this relationship and contains elements of trust, caring, empathy, respect, and understanding. Therapeutic alliance has demonstrated a positive impact on specific

childhood illnesses. In children with juvenile idiopathic arthritis, strong therapeutic alliance is associated with a high level of treatment adherence.⁴ In young patients with eating disorders, a strong alliance between families and clinicians is associated with better overall treatment outcomes.⁵

In adult oncology settings, therapeutic alliance between the patient's informal family caregivers and the oncologist has been associated with better caregiver experiences with their relative's end-of-life care,⁶ and patient-oncologist alliance has been associated with better mental health and emotional wellbeing among caregivers during bereavement.⁷ In the adult intensive care unit (ICU), therapeutic alliance is highest when family caregivers have trust in their ICU team, when high-quality communication occurs, and when there is less conflict at times of decision making.⁸ Alliances with caregivers are also stronger when patient care is perceived as patient-centered.⁸

In the PICU, a strong alliance between parents and pediatric intensivists may lessen parental symptoms of complicated grief after a child's death.⁹ Complicated grief, also referred to as prolonged grief disorder, is a maladaptive form of grief characterized by an intense yearning and preoccupation with the deceased, as well as a loss of meaning or purpose without the deceased.¹⁰ Symptoms of complicated grief overlap with symptoms of acute normative grief but are severe enough to interfere with daily functioning over months to years. The prevalence of complicated grief is estimated to be 6-9% in bereaved adults.¹⁰ Among parents whose children die in PICUs, greater than 50% have symptom levels consistent with complicated grief at 6 and 13 months after their child's death.^{8,10} Parents whose children die a sudden and unexpected death and those with shorter PICU stays have greater symptoms of complicated grief.¹¹ Additionally, parents with insecure attachment styles (i.e., discomfort relying on others or having others rely on them) also have increased risk for complicated grief.¹¹

Difficult relationships between families and medical providers are highly distressing for both parents and providers.¹² Parents report that a core contributor to these difficulties includes lack of a connection or shared understanding with providers, while medical providers describe issues such as confrontational parent advocacy as a source of strained relationships.¹² Communication remains an integral component of high-quality medical care and strong therapeutic alliance. Thus, the parent-physician relationship can be harmed when breakdowns in communication occur across teams or during transitions of care.¹³ Alliances can also be damaged when parental knowledge and perspective are undervalued.¹³ Parents of children at the end of life require communication that is sensitive, caring, and honest.¹⁴ They also require frequent updates on their child's condition to aid their decision making.¹⁴ Meeting these communication needs at a child's end of life fosters trust and can strengthen alliances between families and medical providers.

Trust, honest communication, and mutual respect are all key aspects of therapeutic alliance, and barriers to these attributes have consistently been identified when examining health inequities in medicine among historically marginalized communities in the United States.^{15,16,17} In the field of pediatrics, medical mistrust and poor communication have been described as factors contributing to racial differences in parental decision making at the end of a child's life.¹⁸ Additionally, bereaved Black parents form weaker alliances with pediatric intensivists, putting them at higher risk for poor mental health outcomes after their child's death in the PICU.¹⁹ Latinx families report experiences with discrimination as a barrier to receiving pediatric palliative care services.¹⁶ For Latinx families who immigrate to the U.S., limited English proficiency and infrequent access to interpreter services can lead to miscommunication, increased parental distress, and medical mistrust for families in need of palliative care.¹⁶

Kaye and colleagues identified seven physician characteristics associated with building and sustaining therapeutic alliance with families of children with progressive cancer.²⁰ Physicians that formed strong alliances were those that made human connection with families by recalling personal stories of the patient, those who were mindfully present in each moment, those who were inclusive and demonstrated shared decision making, those who used humor, were honest, and finally those with strong family partnership (i.e., families never felt abandoned).²⁰ In situations where an alliance has been broken, strategies such as exploring the family's experience of the fracture,

acknowledging their perspective, and focusing on the family's future emotional experience may be helpful.²¹ At the end of a child's life in a PICU, evidence suggests that parents who perceive greater fulfillment of their physical, emotional, psychosocial, and environmental needs by medical providers experience less mental health symptoms during bereavement including complicated grief.²²

Building alliances with families from historically marginalized backgrounds requires a lifelong commitment to ongoing self-awareness and improvement. Multicultural competence is the ability to understand and relate to the uniqueness of others in light of the diverse cultures that influence their perspective.²³ It includes aspects of cultural awareness and education, as well as identification and ownership of implicit biases.²³ Providers that develop multicultural competence, in addition to expressing a belief in equality and empowerment, minimize the perception of discrimination and form stronger therapeutic alliances with marginalized patients and families.^{16,23} Similarly, demonstrating empathy, positive regard, and genuineness can build or strengthen these alliances.²³

Therapeutic alliance is a vital component to caring for families, especially at the end of a child's life in the PICU. A strong parent-physician alliance can promote improved emotional well-being among parents and lessen mental health symptoms during bereavement.^{6,9} Strained relationships that impair therapeutic alliance between parents and pediatric providers exist, particularly in situations where communication breaks down or when parents feel undervalued.¹² Providers that form a human connection with families, practice shared decision making, and demonstrate strong partnership with families are likely to strengthen alliances with families.²⁰ Parent-physician alliances with parents from historically marginalized background have been negatively impacted by issues with medical mistrust, poor communication, and perceived parental discrimination.^{16,18,19} Overcoming these barriers to form alliances with parents from marginalized backgrounds requires the development of multicultural competence and a belief in equality and empowerment.²³ These alliances are likely to be further strengthened by physicians who possess empathy, positive regard, and genuineness for the families in their care.²³

References

1. Abela KM, Wardell D, Rozmus C, et al: Impact of pediatric critical illness and injury on families: An updated systematic review. *J Pediatr Nursing* 2020; 51:21-31
2. Butler AE, Hall H, Copnell B. The changing nature of relationships between parents and healthcare providers when a child dies in the paediatric intensive care unit. *J Adv Nurs* 2018; 74:89-99
3. Malhotra S, Chauhan N (2020). The therapeutic alliance between the child, parents, and health professionals. In A. Gallagher, C. Bulteau, & J.L. Michaud (Eds.). *Handbook of Clinical Neurology, Vol. 174 (3rd series) Neurocognitive Development: Disorders and Disabilities* (pp. 323-332). Amsterdam, The Netherlands: Elsevier B.V.
4. Lohsa A, Lemelle I, Pillet P, et al: Therapeutic alliance is associated to treatment adherence in children with juvenile idiopathic arthritis. *Joint Bone Spine* 2021; 88(105151):1-6
5. Graves TA, Tabri N, Thompson-Brenner H, et al: A meta-analysis of the relation between therapeutic alliance and treatment outcome in eating disorders. *Int J Eat Disord* 2017; 50:323-340
6. An AW, Ladwig S, Epstein RM, et al: The impact of the caregiver-oncologist relationship on caregiver experiences of end-of-life care and bereavement outcomes. *Support Care Cancer* 2020; 28:4219-4225
7. Trevino KM, Maciejewski PK, Epstein AS, et al: The lasting impact of the therapeutic alliance: Patient-oncologist alliance as a predictor of caregiver bereavement adjustment. *Cancer* 2015; 121:3534-3542
8. Huff NG, Nadig N, Ford DW, et al: Therapeutic alliance between the caregivers of critical illness survivors and

- intensive care physicians. *Ann Am Thorac Soc* 2015; 12:1646-1653
9. Suttle ML, Hall MW, Pollack, MM et al; Eunice Kennedy Shriver National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network. The impact of therapeutic alliance on parental health outcomes following a child's death in the pediatric intensive care unit. *J Pediatr Intensive Care* 2022 (in press)
 10. Wilson DM, Darko EM, Kusi-Appiah E, et al: What exactly is "complicated" grief? A scoping research literature review to understand its risk factors and prevalence. *Omega (Westport)* 2020; 1-17 [Online ahead of print]
 11. Suttle M, Hall MW, Pollack, et al: Complicated grief, depression and post-traumatic stress symptoms among bereaved parents following their child's death in the pediatric intensive care unit: A follow-up study. *Am J Hosp Palliat Care* 2022; 39:228-236
 12. Mack JW, Ilowite M, Taddei S: Difficult relationships between parents and physicians of children with cancer: A qualitative study of parent and physician perspectives. *Cancer* 2018; 675-681
 13. Greenway TL, Rosenthal MS, Murtha TD, et al: Barriers to communication in a PICU: A qualitative investigation of family and provider perceptions. *Pediatr Crit Care* 2019; 20:e415-e422
 14. Meert KM, Eggly S, Pollack M, et al: Eunice Kennedy Shriver National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network. Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. *Pediatr Crit Care Med* 2008; 9:2-7
 15. Cuevas AG, O'Brien K, Saha S: African American experiences in healthcare: "I always feel like I'm getting skipped over." *Health Psychol* 2016; 35:987-995
 16. Muñoz-Blanco S, Raisanen JC, Donohue PK, et al. Enhancing pediatric palliative care for Latino children and their families: A review of the literature and recommendations for research and practice in the United States. *Children (Basel)* 2017; 5(1):2
 17. McMurty CL, Findling MG, Casey LS, et al: Discrimination in the United States: Experiences of Asian Americans. *Health Serv Res* 2019; 54:1419-1430
 18. Harris VC, Links AR, Walsh J, et al: A systematic review of race/ethnicity and parental treatment decision-making. *Clin Pediatr (Phila)* 2018; 57:1453-1464
 19. Suttle ML, Hall MW, Pollack, MM et al; Eunice Kennedy Shriver National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network. Therapeutic alliance between bereaved parents and physicians in the PICU. *Pediatr Crit Care Med* 2021; 22:e243-e252
 20. Kaye EC, Rockwell S, Woods C, et al: Facilitators associated with building and sustaining therapeutic alliance in advanced pediatric cancer. *JAMA Network Open* 2021; 4(8):e2120925
 21. Eubanks CF, Burckell LA, Goldfried MR: Clinical consensus strategies to repair ruptures in the therapeutic alliance. *J Psychother Integr* 2018; 28:60-76
 22. Meert KL, Templin TN, Michelson KN, et al: The bereaved parent needs assessment: A new instrument to assess the needs of parents whose children died in the pediatric intensive care unit. *Crit Care Med* 2012; 40:3050-3057
 23. Davis TA, Ancis JR, Ashby JS: Therapist effects, working alliance, and African American women substance users. *Cultur Divers Ethic Minor Psychol* 2015; 21:126-135

Companioning Families Of Children With Severe Neurological Impairment: Opportunities To Teach Pediatric Trainees Grief-Informed Care

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Background

Among families of children with severe neurological impairment (SNI), grief begins long before the end of life.¹ With static or progressive central nervous system disorders that result in cognitive and motor impairment and medical complexity, many children with SNI experience frequent fluctuations in health status along their illness trajectories due to both chronic health decline and acute exacerbations.^{2,3} Accordingly, even as families of children with SNI find much to celebrate along the way, loss is often central to their illness experiences. Compounding the

potential for worsening disease status and decline in baseline function for the child, family members can lose personal and collective family identity; a sense of safety, predictability, and control in the world; and freedom to pursue personal goals, travel, and rest.^{1,4}

In the United States, children with SNI comprise <1% of the pediatric population but account for nearly a third of hospital admissions at pediatric centers, and approximately half of these children are cared for at end of life in acute care settings or the intensive care unit.^{3,5} The frequency with which children with SNI interface with inpatient healthcare teams offers an opportunity—and arguably an obligation—for professional caregivers to address the losses families experience throughout their child’s illness course. Unfortunately, the limited medical education focused on understanding patients’ and families’ illness experiences and the existential challenges they face leaves healthcare providers poorly equipped to support families as they recognize, process, and cope with these losses.^{6,7,8}

“Companioning” is a model described in the bereavement literature that reflects a humanistic approach to grief-informed care.^{11,12} It is rooted in a philosophical framework that recognizes grief as an adaptive, nonpathological response to loss. As such, it views grief not as a condition to be resolved but as a process that evolves, and in doing so, it explicates the companion’s role as one of validating, normalizing, and witnessing the griever’s journey in the service of cultivating a therapeutic relationship.

Pediatric trainees, including residents and fellows, have the potential to play an important role in companioning families through loss; however, they face challenges connecting with patients with SNI and their families and providing grief-informed care.^{9,10} In this article, we explore these challenges and provide specific recommendations for ways to more fully engage pediatric trainees in companioning children and families who are navigating ongoing loss.

Barriers to Pediatric Trainees’ Understanding of the Lived Experience of Illness

Pediatric trainees face a myriad of barriers to connecting with children with SNI and their families (Table 1). The nature of pediatric trainees’ interactions with patients and families makes engagement with children with SNI and their families especially challenging. Given that such interactions take place primarily during hospitalizations, trainees’ involvement tends to be fragmented—in direct contrast to those patients’ and families’ life-long illness trajectories. This pattern is a barrier to trainees’ development of deep and longitudinal understanding of patient and family experiences, both because they do not get exposure to what a family’s life is like outside of the hospital—including what a child is like when well (i.e., their “baseline”) and what makes their lives meaningful. Additionally, they are not often privy to ongoing conversations between the family and their multidisciplinary team.^{13,14} Jumping in to care for a patient and family amidst other clinicians with longitudinal, existing relationships can be overwhelming for trainees—and at times, it even feels counterproductive. Some trainees have described worrying about “opening a can of worms” by directly discussing a patient’s setbacks during a hospitalization. Recognizing the incurability of many SNI conditions and the difficulties inherent in managing hard-to-treat symptoms, trainees may feel disempowered to make a difference for the patient and family.^{9,10} Further, the tasks that comprise clinical care as a trainee working on an inpatient service or in a busy clinic (e.g., placing orders for medications and tests, attending to acute symptom management, coordinating care, and getting through the required questions during a brief clinic visit) impede deeper conversations about personal experiences, hopes, fears, and losses.¹⁰ As a result, trainees have limited opportunities to take the lead on engaging families about their experiences including both the challenges and the joys of caring for a child with SNI.

Additionally, pediatric trainees have limited education on how to address loss with patients and families.^{15,16} Due to the limited number of coordinated, integrated bereavement programs in children's hospitals nationwide, residents and fellows often complete clinical training without being exposed to models of multidisciplinary bereavement care. Among children with SNI, unexpected death or death at home often occurs, making support for families through the end of their child's life even more foreign to pediatric trainees and seemingly outside the scope of hospital-based physicians.^{17,18} Further, while attention has been called to hospitals' ethical responsibility to continue caring for families through bereavement,¹⁹ division of labor around bereavement support for families after a child's death is often unclear, particularly given that children with SNI receive services from numerous sub-specialties throughout the healthcare system. Each team's determination that bereavement care is "someone else's job" may ultimately lead to families not receiving the bereavement support they need after a child's death and trainees never witnessing bereavement care provision. This is concerning, as families report that they want to hear from their child's clinicians after their child dies and maintain these relationships in some small way.¹⁸

Opportunities for Mutually Beneficial Engagement Between Pediatric Trainees and Families of Children with SNI

Caring for children with SNI may be an important opportunity to teach pediatric trainees about how to companion families through the ongoing losses and anticipatory grief that are intrinsic to their child's illness. Understanding shifts in baseline health can help inform pediatric trainees about how to recognize and acknowledge the losses that are generated by those shifts. Residents are often the first points of contact for children with SNI and their families during acute illness, as well as providing care for patients throughout all hours of the day, particularly at night when existential concerns loom large.

Pediatric trainees are also an important resource for supporting families of children with SNI. Data suggest that when trainees attend to the lived experiences of illness and loss, parents notice and report that it positively influences their child's and family's care.^{1,9} Parents who have experienced this level of attunement feel supported, heard, and validated in their care of and concerns about their child.⁴ They also report feeling that their child is "seen" and that their quality of life, the challenges they are facing, and the things that give meaning and purpose in their parent-child relationship are acknowledged.^{1,4}

Caring for children with SNI in a way that attends to the many losses families must navigate from diagnosis through bereavement encourages a humanistic approach to practice in which trainees are not only invited into more meaningful clinical encounters, but also afforded the opportunity to learn from parents as teachers. Further, attending to these existential concerns can help pediatric trainees appreciate the value of therapeutic presence and recognize that, in the context of caring for children with life-limiting conditions, their most important interventions may have more to do with listening, witnessing, and accompanying, rather than fixing or curing.⁹

Ultimately, there may be significant benefits to integrating pediatric trainees in grief and bereavement care as a standard part of pediatric practice—both for the trainees and for the families for whom they care. Engagement between trainees and families of children with SNI may assuage the challenges families face secondary to exhaustion, being overwhelmed, and becoming isolated from living with acute-on-chronic losses; the work of extensive hands-on caregiving; vigilance regarding their child's needs; balance of siblings' and other family members' needs; and advocacy for services and supports.^{1,4} Training in companionship and the provision of bereavement care can facilitate accompanying families through losses throughout the illness trajectory in ways that are also deep and enriching for pediatric trainees on their own personal and professional journeys. Accordingly, it is essential to develop educational strategies integrating longitudinal engagement with families of children with SNI in a way that confers the approach of companionship into standard pediatric training.

Recommended Strategies

Training in grief-informed care with a focus on companioning can build pediatric clinicians' capacity to walk with families through loss, from diagnosis through bereavement. Figure 1 illustrates the core components of the companioning model. It is important to note that learning how to stay centered as clinicians, so that one can be present to others' suffering without becoming overwhelmed by it, is fundamental to the art of companioning. As such, incorporating training in awareness-based and contemplative practices is an integral part of this process.^{20,21}

Teaching pediatric trainees how to companion families throughout the illness trajectory and through bereavement can enhance both residents' and families' experiences. Table 2 elucidates strategies for teaching pediatric trainees how to attend to loss, both throughout the illness course before a child dies and after a child dies in the bereavement period. Specific recommendations for condolence letter writing are shown in Table 3. A possible structure for condolence phone calls is depicted in Figure 2. These concrete skills can be taught to pediatric residents and fellows and practiced to enhance their capacity to support patients and families.

For all companioning-focused and bereavement outreach with families, taking the time to listen deeply without distraction, allowing for silence, and tending to emotion are recommended. Additionally, honesty about what one will do going forward (e.g., call in a week, talk with additional providers, attend funerals) should be prioritized above over-promising or committing. Similarly, boundaries are important to consider, with mindful attention to ensuring that the clinician's emotional response to the loss does not interfere with their capacity to hold space for the family's emotional processing.

Importantly, when we succeed in supporting pediatric residents and fellows in developing the skill set needed to engage with families of children with SNI around their experiences of loss, those trainees then have the opportunity to share these skills with other professional caregivers who have less experience providing grief-informed care. In exchange, pediatric trainees can benefit from apprenticing and partnering with interdisciplinary colleagues in social work, child life, spiritual care, and psychology, who are skilled in companioning practices.

Summary

Grief-informed care for children with SNI and their families is lacking, and pediatric residents and fellows have an opportunity to play a crucial role in bolstering the support families receive throughout their child's illness trajectory. This article recommends several strategies for engaging pediatric trainees in grief-informed care that both recognizes the losses families of children with SNI are navigating and supports those families' processes of adaptation. These recommendations are aimed at building pediatric trainees' skills for connecting with families of pediatric patients more meaningfully throughout the illness trajectory, from diagnosis through bereavement. Providing pediatric trainees with concrete skills, role modeling, and educational opportunities to develop practices and confidence in the art of companioning can strengthen pediatric clinicians' practice of grief-informed care, yielding more effective relationship-centered care for patients with SNI and their families.

References

1. Bogetz JF, Trowbridge A, Lewis H, et al. Parents Are the Experts: A Qualitative Study of the Experiences of Parents of Children with Severe Neurological Impairment During Decision-Making. *J Pain Symptom Manage*. Published online June 2021:S0885392421003870. doi:10.1016/j.jpainsymman.2021.06.011
2. Allen J, Brenner M, Hauer J, Molloy E, McDonald D. Severe Neurological Impairment: A delphi consensus-based definition. *Eur J Paediatr Neurol*. 2020;29:81-86. doi:10.1016/j.ejpn.2020.09.001
3. Berry JG, Poduri A, Bonkowsky JL, et al. Trends in Resource Utilization by Children with Neurological Impairment in the United States Inpatient Health Care System: A Repeat Cross-Sectional Study. *PLoS Med*. 2012;9(1):e1001158-10.
4. Bogetz JF, Lewis H, Trowbridge A, Jonas D, Hauer J, Wilfond BS. From Monochromatic to Technicolor: Parent Perspectives on Challenges and Approaches to Seeing Children with Severe Neurological Impairment Holistically. *J Palliat Med*. Published online September 22, 2021. doi:10.1089/jpm.2021.0344
5. DeCoursey DD, Silverman M, Oladunjoye A, Balkin EM, Wolfe J. Patterns of Care at the End of Life for Children and Young Adults with Life-Threatening Complex Chronic Conditions. *J Pediatr*. 2018;193:196-203.e2. doi:10.1016/j.jpeds.2017.09.078
6. Johansen ML, Holtedahl KA, Davidsen AS, Rudebeck CE. "I deal with the small things": the doctor-patient relationship and professional identity in GPs' stories of cancer care. *Health Lond Engl* 1997. 2012;16(6):569-584. doi:10.1177/1363459312438565
7. Tait GR, Hodges BD. End-of-life care education for psychiatric residents: Attitudes, preparedness, and conceptualizations of dignity. *Acad Psychiatry J Am Assoc Dir Psychiatr Resid Train Assoc Acad Psychiatry*. 2009;33(6):451-456. doi:10.1176/appi.ap.33.6.451
8. MacLeod RD. On reflection: doctors learning to care for people who are dying. *Soc Sci Med* 1982. 2001;52(11):1719-1727. doi:10.1016/s0277-9536(00)00289-6
9. Bogetz JF, Bogetz AL, Rassbach CE, Gabhart JM, Blankenburg RL. Caring for Children With Medical Complexity: Challenges and Educational Opportunities Identified by Pediatric Residents. *Acad Pediatr*. 2015;15(6):621-625. doi:10.1016/j.acap.2015.08.004
10. Bogetz JF, Bogetz AL, Bergman D, Turner T, Blankenburg R, Ballantine A. Challenges and Potential Solutions to Educating Learners About Pediatric Complex Care. *Acad Pediatr*. 2014;14(6):603-609. doi:10.1016/j.acap.2014.06.004
11. Wolfelt, A. *Companioning the Bereaved: A Soulful Guide for Caregivers*. Companion Press; 2006.
12. Schuurman, D. L., & Mitchell, M. B. (2020). *Becoming grief-informed: A call to action*. Dougy Center: National Grief Center for Children & Families. www.dougy.org
13. Edwards JD, Davidson EJ, Houtrow AJ, Graham RJ. Pediatric resident attitudes toward caring for children with severe disabilities. *Am J Phys Med Rehabil*. 2010;89(9):765-771. doi:10.1097/PHM.0b013e3181ec9936
14. Nazarian BL, Glader L, Choueiri R, Shipman DL, Sadof M. Identifying what pediatric residents are taught about children and youth with special health care needs and the medical home. *Pediatrics*. 2010;126 Suppl 3:S183-189. doi:10.1542/peds.2010-1466O
15. Wraight CL, Eickhoff JC, McAdams RM. Gaps in Palliative Care Education among Neonatology Fellowship Trainees. *Palliat Med Rep*. 2021;2(1):212-217. doi:10.1089/pmr.2021.0011
16. Porter AS, Weaver MS, Snaman JM, et al. "Still Caring for the Family": Condolence Expression Training for Pediatric Residents. *J Pain Symptom Manage*. 2021;62(6):1188-1197. doi:10.1016/j.jpainsymman.2021.05.019

17. Johnston EE, Bogetz J, Saynina O, Chamberlain LJ, Bhatia S, Sanders L. Disparities in Inpatient Intensity of End-of-Life Care for Complex Chronic Conditions. *Pediatrics*. 2019;143(5):e20182228. doi:10.1542/peds.2018-2228
18. Bogetz JF, Revette A, Rosenberg AR, DeCoursey D. "I Could Never Prepare for Something Like the Death of My Own Child": Parental Perspectives on Preparedness at End of Life for Children With Complex Chronic Conditions. *J Pain Symptom Manage*. 2020;60(6):1154-1162.e1. doi:10.1016/j.jpainsymman.2020.06.035
19. Lichtenthal WG, Sweeney CR, Roberts KE, et al. Bereavement Follow-Up After the Death of a Child as a Standard of Care in Pediatric Oncology. *Pediatr Blood Cancer*. 2015;62 Suppl 5:S834-869. doi:10.1002/pbc.25700
20. Meier DE, Back AL, Morrison RS. The Inner Life of Physicians and Care of the Seriously Ill. *JAMA*. 2001;286(23):3007-3014. doi:10.1001/jama.286.23.3007
21. Halifax J, Byock I. *Being with Dying: Cultivating Compassion and Fearlessness in the Presence of Death*. Reprint edition. Shambhala; 2009.
22. Jewish Lights: A Time to Mourn, a Time to Comfort, 2nd Ed. Accessed March 25, 2022. <http://www.jewishlights.com/page/product/978-1-58023-253-1>

Table 1. Barriers to connections between pediatric residents and children with SNI and their families

Category	Specific Facets
Nature of trainee interactions with families of children with SNI	<ul style="list-style-type: none"> ■ Fragmented rhythm of hospitalizations ■ Hospital- or clinic-based interactions without view into life beyond the clinical space ■ Limited insight into ongoing, longitudinal conversations Fear of "opening a can of worms" ■ Lack of confidence and comfort in exploring existential challenges and attending to grief ■ Pressure to complete tasks and see patients quickly ■ Assumption that there is little to add given parent expertise about their child's needs
Lack of coordinated, integrated grief-informed care, including bereavement care	<ul style="list-style-type: none"> ■ Limited education for residents on addressing loss with bereaved parents ■ Bereavement care not considered part of standard care ■ Lack of exposure to role modeling of bereavement care provision ■ Unexpected deaths and/or deaths at home feel foreign to residents and beyond scope of hospital-based physicians ■ Narrow conceptualization of bereavement care as solely following death rather than as part of a continuum of grief-informed care centered on companioning

Figure 1. Central tenets of companioning bereaved parents and families

**Adapted from Alan Wolfelt's Companioning the Bereaved*



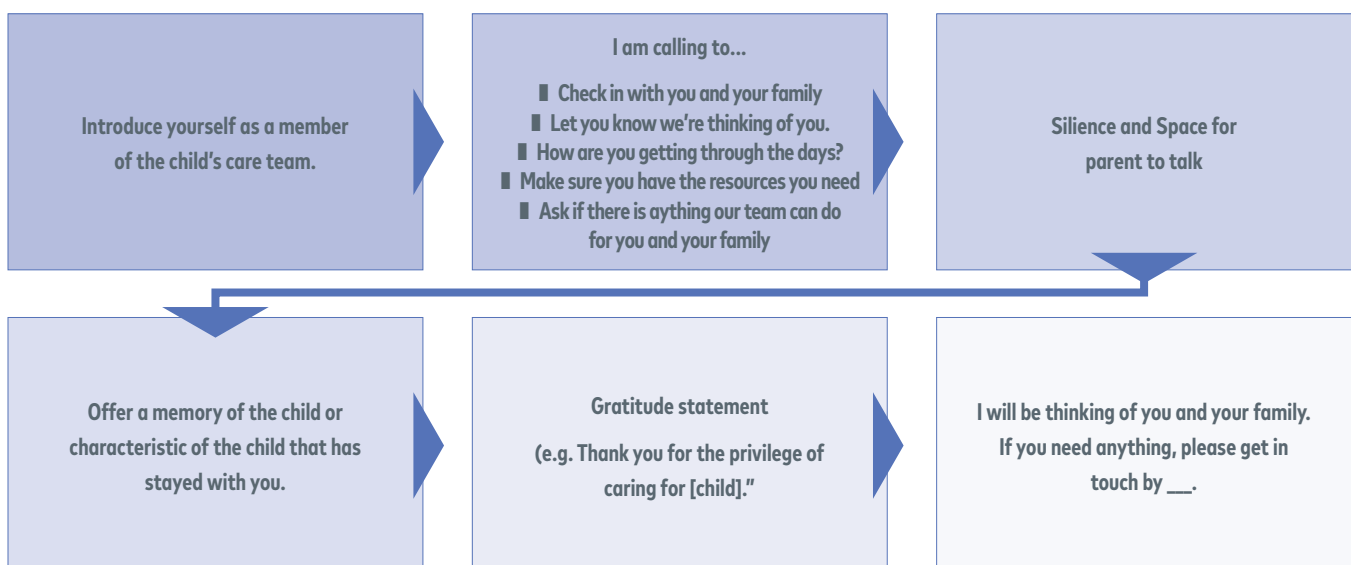
Table 2. Strategies for teaching pediatric trainees how to attend to loss

Before a child's death, throughout the illness course	After a child's death, throughout the bereavement period
<ul style="list-style-type: none"> ■ Allotting protected time for pediatric trainees to connect with and talk with children and their families ■ Virtual or in-person "home visits" with families in their home spaces ■ Opportunities for interaction between trainees and Family Advisory Councils ■ Education and skill development in grief-informed care 	<ul style="list-style-type: none"> ■ Allotting time for bereavement follow-up as part of trainee responsibilities ■ Offering trainees clinical rotations with bereavement programs (i.e., inpatient multidisciplinary programs, social work- or psychology-run support groups) ■ Exposing trainees to best practices used by multiple disciplines (e.g., social work, child life, palliative care, hospice, psychology) ■ Creating a culture that models and normalizes condolence expression and bereavement follow-up as part of standard of care ■ Instruction on condolence expression (e.g., letters, phone calls, memorial service attendance, etc.)

Table 3. Sample text for condolence letter writing²²

Letter Element	Option 1	Option 2	Option 3
Greeting	Dear [parents' first names]	Dear [Mr./Mrs./Ms./Dr./ etc.]	Dear [last name] Family
Naming the deceased and expression of emotion	I was so saddened to hear that [patient's name] died.	There are no words to express my sadness in response to [patient's] death.	[X] shared the news of [patient's] death with me, and I wanted to express my deep sorrow.
Communication of sympathy and thoughts focused on family	You and your family are in my thoughts.	Please know that you and your family are in my prayers.	I am thinking of you and sending wishes for peace for you and your family.
Memory/story/achievement	I will always remember...	[Patient's name] was such an excellent [X]...	[Patient's name] had truly notable [character trait]...
Message to non-parent family member	Please pass my condolences on to your parents...	Please tell [sibling's name] that I am thinking of...	Please tell your entire family that the team at [hospital or clinic] is holding them in our hearts.
"Good parent" statement or acknowledgment of strengths	It was always wonderful to see how deeply you cared for [patient's name], [sibling's name], and each other, even amidst tremendous stress.	I always admired how you cared for [patient's name] with so much love and thoughtfulness.	Your capacity to care for [patient's name] alongside all of your other roles and responsibilities is remarkable; you are extraordinary/ parents.
Conclusion	With deep care,	With wishes for comfort,	From our hearts to yours,

Figure 2. Best practices for condolence phone calls



An Introductory Review of the Utilization of Creative Art

Therapies in Bereavement with Children

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Just as it is for adults, there is no "right way" for children to grieve. There is no timeline and certainly no rule book. The manner in which children experience grief and loss can vary widely based on the type of loss, experience of the loss, coping strategies, child development, family system, and supports in place. Each factor presents a unique opportunity to explore approach and response. Though children are typically oriented in the concrete, there is still often a beautiful connection that can be found in the abstract arts. Techniques utilized in the creative arts inclusive of art, dance/movement, music, and play therapies provide space for identification and exploration of emotions while simultaneously providing a space both for expression and coping.

The National Alliance for Children's Grief (NACG) provides numerous resources in assisting children, families, and professionals in navigating grief and loss. In their resource titled "10 Ways to Help a Grieving Child," tips are outlined including: be honest; listen; acknowledge the child's grief; share your own experience; maintain clear expectations and boundaries; provide reassurance; create rituals and family traditions; and be patient. The creative arts, especially when utilized within a therapeutic environment by certified and licensed individuals, offers the chance to touch on these various aspects of grief and loss. In fact, one notable tip even specifically outlines the importance of being creative through activities such as drawing, writing, doing crafts, listening to music, and playing games as it provides an outlet to express feelings (Gabbay, 2020). Additionally, the disarming nature of the arts provides an environment to learn the tools to continue moving through grief and allows a safe environment in exploring the tasks of mourning in a child-friendly manner. The inherent flexibility in creativity found in activities and the arts that allows for processing and exploring of emotions and experiences. This review provides an opportunity to better understand the mission and purpose behind creative art therapies and offers a brief introduction as to how they can be utilized within a bereavement framework.

Art Therapists (ATR or ATR-BC) are masters-level clinicians that utilize various mediums of art to create, interpret, and explore a client's needs. Art Therapy as defined by the American Art Therapy Association is "an integrative mental health and human services profession that enriches the lives of individuals, families, and communities through active art-making, creative process, applied psychological theory, and human experience within a psychotherapeutic relationship (AATA, 2022). There is an allowance for deeper processing of feelings when providing a child the space to create with color, lines, medium, and device. Although there is certainly space for the art therapist to interpret meaning behind creations, there is also freedom for the child themselves to interpret the meaning and thus provide additional insight into their experience and perspective. Art Therapy also provides an outlet for non-verbal expression. As children do not always have the language to verbally participate

in expression, non-verbal activities inclusive of Art Therapy can be extremely beneficial at “letting it out” in a productive, safe, and healthy manner. Techniques utilized within Art Therapy can allow for better processing and exploring of experiences in bereavement with the development of a tangible product that exemplifies the child’s understanding and can potentially be used within a family-centered context to initiate conversation surrounding the loss.

Since 1966, the American Dance Therapy Association has advocated for the effectiveness of using movement with individuals, including children, to explore the connection between body and mind. The association defines dance/movement therapy as “the psychotherapeutic use of movement to promote emotional, social, cognitive, and physical integration of the individual” (ADTA, 2020). There are strong neurological processes involved in connecting movement to thought. For example, learning simple movements in conjunction with a song has been shown to improve recall and memory of the song itself. Many have discussed the idea of a “runners high”—the out-of-body experience that can happen when engaging in high-intensity cardiovascular activity that leads to a surge of dopamine and endorphins. In bereavement, providing space for movement to occur allows another non-verbal method of connecting with the experience. New insight might be gained by providing the freedom that exists through movement, breaking through potential mental barriers that could exist in the child, and offering a method of expressing energy that might be restricted. Dance/Movement Therapists possess the unique insight into interpreting those movements and starting a conversation on (quite literally) moving through the grief.

The American Music Therapy Association defines Music Therapy as “an established health profession in which music is used within a therapeutic relationship to address physical, emotional, cognitive, and social needs of individuals” (AMTA, 2022). The assessment process of board-certified music therapists (MT-BC) allows for a look at the entire individual. Much like art therapy, music therapy also provides the opportunity for product creation. This allows for the therapeutic process of creating through improvisation, songwriting, music listening, and other interventions in a non-threatening context. The product that is then created can act as a tool to continue conversations within a family context, create a sense of mastery, and be utilized as measure of both success and progress towards goals.

One of the most fundamental activities for social, cognitive, and emotional development in children is play. Through connections made within the context of play, there is an opportunity to communicate on a more effective and basic level with children while also providing simultaneous outlets for energy release, projection, storytelling, and processing. The Association for Play Therapy (APT) was established in 1982 and works to communicate and foster relationships among qualified professionals that might utilize play therapy in their own clinical work. The APT defines Play Therapy as “the systematic use of a theoretical model to establish an interpersonal process wherein trained Play Therapists use the therapeutic powers of play to help clients prevent or resolve psychosocial difficulties and achieve optimal growth and development.” Play Therapy provides a non-threatening way to explore the grief experience and gain insight into the perspective of the child about what death is, what it looks like within their family system, and how they cope with the stressors related to grief and loss. As an assessment tool, play can be extremely beneficial at gaining direct insight from the child themselves.

Child Life has been an integral part of many children’s hospitals throughout the country as they assist in navigating the medical paradigm from a child-centered perspective. Child Life specialists (CCLS) frequently utilize tools as aforementioned to provide support within the scope of their role. Although historically the understanding of the Child Life role has been limited to working with children actively seeking treatment for an illness, there is a robust use of certified Child Life specialists in anticipatory bereavement and bereavement work. Child Life is defined by the Association for Child Life Professionals (2020) as promoting “optimal development of children, families and their support systems, and reduces the impact of adverse childhood healthcare events.” This holistic view on providing care is ideal in bereavement as it integrates the child into the family and works within that context to provide care. Child Life specialists act as a conduit for support, assessing psychosocial and

development needs in addition to acting as an advocate from a child-centered perspective within the healthcare environment. There is a greater chance of success when collaborating with Child Life specialists that may have been involved in the child's life. For example, a Child Life specialist may already be involved if a child is part of the family system in a hospital setting. In this case, there has likely already been an assessment of the child's coping, processing, and involvement within the family system. This can provide better insight into what techniques and approaches will benefit the child in a bereavement context.

Each creative arts profession explored in this introductory review offers unique and specialized ways to connect, assess, and treat children experiencing grief and loss. However, a commonality found in each is the importance of utilizing a trained, certified, and/or licensed professional in their respective field, as it allows for a deeper and more effective method of treatment. Access can unfortunately be limited in locating creative arts therapists, but there is still an opportunity to utilize methodologies and integrate these complementary techniques into bereavement practice within the clinician's scope of practice. Whether bereavement care is geared towards a child or an adult, the primary goal is to find a way for the client to identify, express, process, and release symptoms of grief and loss and to develop appropriate and effective coping strategies to be utilized moving forward. Finding connection through the arts can assist in building rapport and enrich existing interventions while simultaneously meeting the child where they are at in their grief process.

References

American Art Therapy Association. (2022). *Becoming an art therapist*. <https://arttherapy.org/becoming-art-therapist/>

American Music Therapy Association. (2022). *About music therapy*. <https://www.musictherapy.org/about/>

Association for Play Therapy. (2021). *What is play therapy*. <https://www.a4pt.org/>

Association for Child Life Professionals. (2022). *CL services in healthcare settings*. Child Life Council. https://www.childlife.org/docs/default-source/aclp-official-documents/cl-services-in-healthcare-settings.pdf?sfvrsn=58398c4d_2

Gabbay, P. (2020). *10 ways to help a grieving child*. National Alliance for Children's Grief. <https://childrengrieve.org/resources/10-ways-to-help-a-grieving-child>

Hoyt, L. (2020). *About the American Dance Therapy Association*. American Dance Therapy Association. <https://www.adta.org/about>

Remembrance Photography

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Now I Lay Me Down to Sleep

www.nowilaymedowntosleep.org

Each year in the United States, nearly 40,000 babies are either stillborn or die within the first month of life. Over the past 17 years, Now I Lay Me Down to Sleep (NILMDTS) has linked arms with tens of thousands of families experiencing the loss of a baby by providing the complimentary gift of remembrance photography.

NILMDTS has found that families rarely regret what they did, but they often regret what they didn't do. And while there is a plethora of parenting resources available, very few address parenting in the face of loss. Though it may initially seem counterintuitive to encourage parenting in these situations, it greatly improves the psychosocial outcomes for these families when this type of memory-making is facilitated.

Whether a family's loss is expected or not, parents and family members often find themselves in shock in those moments. They tend to forget to pull out their phone or a camera or they don't even fully realize that they can hold their own baby.

Photographs serve as a bridge to this type of parenting as well as offer healing for years to come. The journal *Illness, Crisis & Loss* says that remembrance photography "did not simply produce mementoes, but invited families into a parenting role, to celebrate their baby's life, to tell their story, and to help make meaning of their experiences in an often overwhelming and chaotic medical space" (Martel & Ives-Baine, 2014).

In 2008, NILMDTS CEO, Gina Harris had just delivered her stillborn son, Ethan. The doctors tried to prepare her and her husband for the condition he would be in but it was even worse than she could have imagined. A year prior, Gina and her husband were at the same hospital with Ethan's big brother, David. David was also stillborn, but his death was due to different causes.

"As bereaved parents, we know firsthand the healing power of having portraits of our son David. Not having photographs of Ethan has made the healing journey more difficult. I only wish we would have captured something of Ethan. Even if it were just his hands and feet, it would have been instrumental in our healing and documenting Ethan's life," said Gina Harris.



Remembrance photography is an important step in the healing journey. Photographs are one of the most precious and tangible mementos parents can have, showing the love and bond that was given and shared with their baby. These portraits will last for generations, and will honor a tiny life that is forever loved and cherished. As a medical professional, it is important to help families experiencing the loss of a baby facilitate these types of services through NILMDTS. Medical personnel should introduce the idea of photographs early and often, contact NILMDTS to see if a local photographer is available to capture images, and encourage families and caregivers to take as many photos as they wish.

Having these moments is especially important for parents in order to help construct the future identity of their family. Many bereaved parents are faced with difficult questions down the road, such as "Do you have any children?" or "How many children do you have?" These are difficult questions to answer because, as outlined in an article in the journal *Death Studies*, "Parents facing early child loss-perinatal death-suffer no less, yet they are faced with the additional burden that their baby is not socially recognized as significant" (Blood & Cacciatore, 2014).

Always encourage them to take pictures above and beyond what NILMDTS, or you as the caregiver, takes. They can never have too many. Let parents know that they never have to look at these pictures or keepsakes, but that they will always have them for when they are ready.

Through educational training courses like NILMDTS' Remembrance Photography as a Best Practice in Perinatal Loss Populations, medical personnel will learn how photography is increasingly becoming a best practice when dealing with perinatal loss and medical providers are educated on the difference these photographs make in regards to psychosocial support moving forward.

In addition, the course covers essential communication skills during such a sensitive time, as well as tips on creating intimate portrait sessions to ensure high quality images. This continuing nursing professional development activity was approved by the Colorado Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.

"As a labor and delivery nurse, the hardest days are the ones where we send families home without the sweet babies they have longed for, nurtured, and loved. The services provided by NILMDTS allow me to assist in supporting those families by honoring the little lives lost. Working with NILMDTS fosters the preservation of memories for these families during a whirlwind of heartbreak," said Registered Nurse, Ada Murdock.

Through interactive demonstrations, providers learn how to offer and/or create an intimate portrait session for a family. The NILMDTS continuing education course is ideal for practitioners in areas that NILMDTS does not currently serve and those in areas that are underserved. The course allows nurses to help serve the families NILMDTS is otherwise unable to reach due to time of day, condition of the baby, and shortened timelines. With the knowledge and skills taught, providers will be able to give their bereaved parents the best patient experience possible under the circumstances.

In order to facilitate as much memory-making as possible, **the following is recommended:**

- If your facility offers care packages for families experiencing loss, introduce that early and go through the contents with them so that they understand everything inside and can incorporate them into the memory-making process.
- Don't forget to capture photographs of the details of the day-room signage, flowers, memory box items, stuffed animals, special clothing, etc.

- Call their baby by name and treat them as you would any baby. Point out features of the baby—cute noses, tiny hands, curly hair. Refer to family members as 'mom,' 'dad,' 'grandma,' 'grandpa,' This may be the first time they've ever heard themselves called by those names.
- Encourage parents to hold their baby as long as they want.
- Have parents dress and diaper their baby, bathe their baby, and brush their baby's hair.
- Take handprints, footprints, and molds (if your facility offers them). Make multiple copies.

Suggestions like these and many more can be found in the NILMDTS course. With the knowledge and skills taught, providers will be able to give their bereaved parents the best patient experience possible under the circumstances. More information can be found at www.nowilaymedowntosleep.org/continuingeducation

Additional Information on NILMDTS:

Now I Lay Me Down to Sleep (NILMDTS) gifts heirloom remembrance portraits to parents experiencing the death of a baby. Since 2005, more than 60,000 families from around the world have received photographs free of charge from NILMDTS.

Testimonials:

"I found this training profoundly helpful. I had a patient pass away just last week and was unable to obtain a photographer due to all of the COVID-19 restrictions. Having this information would have been really helpful!! I feel so prepared now to be able to obtain quality photos in an emergency situation. Even though I took really good notes during the training, my only suggestion would be to generate a tip sheet based on a summary of this information for us to have and share with our Bereavement Committee members in the event they find themselves filling in as the photographer. Thank you!"

–**Amanda Bielata**, NILMDTS Medical Affiliate

"I don't know the name of the nurse who took a few photos for us but I am grateful that she was there. To all the nurses and hospital staff that step out of your roles and into the rooms of grieving families to capture the few moments we have with our babies. Thank you!!!"

–**Krysten Rivera**, Jakob's Mommy

How to Find a Photographer:

NILMDTS will assist in locating a local affiliated photographer to capture images for a bereaved family. If a patient delivers overnight, it is recommended that you call prior to delivery so that a photographer can be arranged for the first thing the next morning. Local photography contacts can be located on the NILMDTS webpage.

Guidelines for Services:

At the request of the parents or medical staff, we will have a NILMDTS affiliated photographer, if available, come to the hospital or hospice location for a private and sensitive photography session. Our affiliated photographers are dedicated to making the photography session as loving, sensitive, and private as possible. When searching for a local NILMDTS photographer visit <http://www.nilmdts.org> for contact information in your area.

NILMDTS photographers provide the free gift of professional quality portraiture. Gently retouched black and white or sepia toned heirloom quality portraits are delivered digitally.

Retouching:

If a NILMDTS photographer is not available, please utilize the Posing Guide for Hospitals and Posing Poster located on the NILMDTS webpage. The guide includes instructions for submitting images for retouching to NILMDTS.



Sources:

Center for Disease and Control Prevention 2020, accessed March 16, 2022, <https://www.cdc.gov>;

March of Dimes 2020, accessed March 16, 2022, It;<https://www.marchofdimes.org>;

Martel, S., & Ives-Baine, L. (2014). 'Most prized possessions': Photography as living relationships within the end-of-life care of newborns. *Illness, Crisis, & Loss*, 22(4), 311-332. <https://doi.org/10.2190/IL.22.4.d>

Blood, C. & Cacciatore, J. (2014). Parental grief and memento mori photography: Narrative, meaning, culture, and context, *Death Studies*, 38(4), 224-233, DOI: 10.1080/07481187.2013.788584

Difficult Decisions in Perinatal Loss

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For many families, pregnancy is a time for joyful preparation. Families work together to prepare their hearts and homes for a new member. Baby supplies are purchased, siblings are prepped to become big brothers and sisters, and baby names are considered. Prenatal appointments present opportunities to hear the baby's heartbeat and ultrasounds are done to learn the baby's gender and see the baby's face.

But all of this can change when there is a serious maternal or fetal diagnosis during pregnancy. There may be a life limiting diagnosis of the baby or one which would result in chronic disability. There may be maternal health complications that may worsen or could threaten maternal mortality if the pregnancy is continued. Multi-gestation pregnancies can be considered high risk and a selective reduction may be considered. In complicated twin pregnancies, a procedure may be offered that results in the loss of one twin in order to save the life of the other.

The prenatal diagnosis of a fetal concern is a unique loss. Families grieve the loss of the expected or anticipated pregnancy. Ultrasounds are now performed to see what is wrong. Preparations are made for meetings with specialists. Decisions must be made regarding goals for care, options for continuing the pregnancy, fetal surgery or treatment, and the possibility of the baby's death or chronic health issues. A time that should be joyous and celebrated with family and friends brings devastation and heartbreak. Even if the baby is expected to survive, the knowledge that there may be the need for surgeries or other treatments is its own kind of loss.

Parents are asked to make a multitude of difficult decisions. They must learn and absorb medication information and technical language, integrate this new learning, and determine what it means to them and their families. Should we end the pregnancy? Continue with the goal of aggressive medical intervention? Provide comfort and palliative care? Attempt fetal surgery? Consider making an adoption plan?

Parents need to be given the opportunity to explore all alternatives in a non-judgmental way, being fully informed of all options. While many families may find comfort in the option of continuing a pregnancy following a life-limiting fetal diagnosis, other families may consider ending the pregnancy early. Aspects of perinatal palliative care planning and perinatal bereavement support can be integrated into the care of these families, as well.

The parents' decision to terminate following a terminal diagnosis is often impacted by concern that the baby is in pain or is suffering, the potential impact on their family or other children in the home, the prognosis of the baby, and the financial implications of ongoing care. The decision to terminate does not mean that the family will not grieve or that they don't love or want their baby. These decisions are heart-wrenching and can be mentally and spiritually devastating to both parents. Parents often struggle with telling family and friends of the decision that they have made. This can both heighten the isolation that they feel and limit their support system.

Access to pregnancy termination services also complicates an already difficult situation. A family may desire a medical induction in a hospital which would allow more options for memory making and bonding with their baby only to learn that those services are not available due to their gestational age, availability of services in their community, or lack of insurance coverage. As legislation is enacted to limit access to pregnancy termination, patients may need to leave their support systems, travel out of state, and may not have the same options for perinatal bereavement care.

Anticipatory grief is quite common with a life-limiting or terminal diagnosis. During the pregnancy, parents often grieve the impending death of their baby or the hardships that will be faced due to the diagnosis. Being connected with a Fetal Care Center and Palliative Care team can provide crucial support, consultation, guidance, and assistance with birth planning, no matter when or how the pregnancy ends. Providing a peer support connection with a family that has had similar circumstances can be a great comfort and an instrumental resource.

Providing examples of what other families have chosen to do can help them to feel more comfortable in providing care for their baby, feel more confident in their decisions, and can help them to identify questions of which they had not yet thought. Sometimes there is nothing that can be said. Bearing witness and sitting with a family may be the most helpful thing you can do.

No matter what choice a family makes, a prenatal diagnosis can be a traumatic experience. Everyone grieves differently and there is no such thing as grieving "perfectly," nor is there one "right" or "best" way to proceed. Families are changed after the death of a baby or the loss of a pregnancy, and it can be a very isolating experience. Feelings of longing and helplessness are common. Joy and visions of the future are replaced with unfulfilled dreams and heartbreak. Many families are never given a medical reason for their loss. The quest for answers and understanding of 'how' or 'why' this happened can be overwhelming and self-blame can be common. Quality perinatal bereavement support is crucial for families as they make decisions, mourn what they have lost, and seek to accept their "new normal."

Family and friends often struggle with what to say or how to help. It is important to remember that they are also grieving. For this reason, seeking support from someone outside of their family or social circle is recommended. Parents and loved ones have limited memories, keepsakes, or opportunities to be with the baby. Providing ongoing aftercare support, memorials, or remembrances will help families lay a foundation for healthy grieving and opportunities to integrate the loss into their lives.

Ongoing support and follow-up with bereaved families are essential for their well-being and healing. Families grieving the death of a baby need empathetic care, knowledge of the grief process, and often advocacy on the choices and rights available to their baby for end-of-life care. Consider referral to specialized support groups and therapists who understand the complicated grief that may accompany perinatal loss when there is a pregnancy termination. Working in the field of perinatal bereavement can be challenging but it is often very inspiring and fulfilling. Providing supportive and compassionate care to families helps them in their future healing.

Helpful things to say to a family after prenatal diagnosis:

"I am so sorry you are going through this."

"I am so sorry for the pain you are experiencing."

"Have you thought about....?"

"Some parents have...."

Tips for the Caregiver

- Relationship-based care helps providers individualize care for families by working to explore their goals, suggesting potential interventions/options/choices, and identifying the family's priorities and concerns.
- Ensuring informed consent of procedure and care options will help to alleviate anxiety and empower the family.
- All perinatal bereavement support practices can and should be offered to all families, including those that have made the decision to terminate following a life-limiting diagnosis.
- There isn't a "best" thing for families to do following a life-limiting fetal diagnosis. There isn't one "right" or "better" way. The role of the caregiver is to support families in making the decision that is most livable for them.
- Some families may want to see or hold their baby, and/or have memory-making opportunities, etc., while others may not want these options. Choices should be offered to parents and presented as options for them to decide what is best for them. Giving parents options and choices in their baby's care helps to provide them with a sense of control.
- Resecting the parents' decisions and choices helps to build trust with the healthcare team. Understand that the choices they make may not be what you recommend, or think is best. Consider that they are making the best decisions they can under these circumstances.
- Having a delivery plan can help to better allow for parents' wishes to be honored and allow for questions and concerns to be honored.
- Parents worry about what the baby will look like, and they may be scared to hold the baby. Educating the family on what to expect and what can be done following delivery is crucial.
- The actual time of delivery can be incredibly challenging. Parents may feel that the act of walking into a surgery department, pushing with a vaginal delivery, or cutting the umbilical cord is contributing to the actual death of their baby and they may find these actions difficult to complete.
- Parents may decide to continue the pregnancy. They should feel supported in this decision, with a new plan of care started, and a continuation of palliative care.
- Keep in mind: State laws, physician practices, and hospital or birthing center restrictions may prohibit the termination of a pregnancy. If a referral to an outside source is being made for the procedure, ensure that supportive bereavement care will be provided.
- As the care provider, it is important that you are aware of your own personal biases and beliefs. If you feel ethically challenged in this care, it is in the best interest of yourself and the family to find them a new caregiver.
- A continuum of care between the healthcare team and the family is the best practice. Having a care team that is fully aware of the family's wishes, preferences, and concerns will aid in the best delivery of care.

Resources for Families

- Healing After a Difficult Decision – a support brochure from Share Pregnancy & Infant Loss Support <http://www.nationalshare.org>
- Healing After a Difficult Decision: Ending a Wanted Pregnancy – Parent Support private & moderated Facebook page
- Perinatal Hospice & Palliative Care <http://www.perinatalhospice.org>
- A Heartbreaking Choice <http://www.aheartbreakingchoice.com/>
- Ending a Wanted Pregnancy www.endingawantedpregnancy.com
- A Time to Decide, A Time to Heal by Molly A. Minnick, Kathleen J. Delp, & Mary C. Ciotta

Professional Resources

- PLIDA Position Statement: Pregnancy Termination Following Adverse Fetal or Maternal Diagnosis www.plida.org
- National Perinatal Association Position Statement: Ethical use of Assisted Reproductive Technologies & Egg Freezing www.nationalperinatal.org
- Difficult Decisions – Share Pregnancy & Infant Loss Support online training <https://nationalshare.org/26454-2/>

References

- Black, B.P., Wright, P.M. & Limbo, R. 2016. *Perinatal & pediatric bereavement in nursing and other health professions*. New York, NY. Springer Publishing.
- Denney-Koelsch, Erin M. & Cote-Arsenault, D. (2020). *Perinatal palliative care: A clinical guide*. New York, NY. Springer Publishing.
- Limbo, R. & Kobler, K. (2016). Moments matter: Exploring the evidence of caring for grieving families and self. *In Perinatal & pediatric bereavement in nursing & other health professions*. ED. Black, B.P., Wright, P.M. & Limbo, R. (pp. 159-181). New York, NY: Springer Publishing,
- Limbo, R. & Kobler, K. (2010). The tie that binds: Relationships in perinatal bereavement. *MCN The American Journal of Maternal/Child Nursing*, 35(6), 316-321.



10 Desired Attributes of a Perinatal Bereavement Program

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While I am now retired, during my career I was frequently asked to provide consultation to parents experiencing the diagnosis of a fetal or neonatal life-limiting condition. Included in my consultations was a discussion about bereavement and a referral to our bereavement services. Prior to my retirement, our organization had a perinatal bereavement process closely linked with our perinatal palliative care consultation. It is from this experience, that I am writing about what I perceive to be ideal attributes of a perinatal bereavement service.

There are over 1 million fetal deaths (miscarriage and stillbirths) yearly in the US. The most recent CDC data noted that the perinatal death rate (>20 weeks' gestation through 7 days after birth) was close to 6 per 1000 live births + fetal deaths. Appropriate bereavement support can improve the outcome of these families.

Bereavement support should be:

1. Continuous

- a. Bereavement doesn't start after the death of the fetus/newborn. From the time of the diagnosis of a potentially life-limiting fetal or neonatal condition, parents benefit from anticipatory bereavement support. Many perinatal centers include bereavement specialists as part of their multidisciplinary high-risk OB teams. The concept of anticipatory bereavement is appropriately addressed during antenatal consultations.
- b. Transitions between providers and sites of care should be seamless

2. Interdisciplinary

- a. OB and pediatric specialists, geneticists, advance practice nurses and physician assistants, OB and NICU nurses, midwives, doulas, ultra-sonographers, bereavement personnel; the list goes on. Each has a role and contributes to the aim of supporting the parents through the pregnancy, delivery, and perinatal death or discharge of the newborn with a life-limiting condition.
- b. The various subspecialties and pediatric palliative care services overlap with bereavement services and should be collaborative

3. Comprehensive: Perinatal bereavement support addresses

- a. Grief over loss of the hoped-for experience of pregnancy and delivery
- b. Grief over the loss of the expected newborn in the first 7 days of life
- c. Anticipatory grief following the diagnosis of a fetus or newborn with a life-limiting condition
- d. Bereavement support includes the psychosocial, spiritual, physical, and practical needs for the parents
- e. Possible bereavement following the death of the fetus or newborn
- f. The team should support recognition of parenthood

4. Inclusive

- a. Bereaved parents are multidimensional and come from different cultures, races, ethnicities, religions, and gender identities. Provide sensitive, individualized care. Inquire about grief and bereavement expressions in their culture or group and how others in their culture/identity group desire to be supported through bereavement.
- b. Acknowledge that mothers and fathers may grieve differently and provide individualized support as needed
- c. Consider needs of siblings, extended family members, and others as needed
- d. Address needs of parents experiencing all perinatal losses
 - i. Fetal death, miscarriage, still birth
 - ii. Termination of pregnancy
 - iii. Neonatal death

5. Inquisitive

- a. Bereavement is not unidimensional. Inquire about what concerns the parents most.
- b. Ask parents about previous experiences with loss
- c. Ask about the meaning of this pregnancy/newborn
- d. Inquire about the impact of the fetus/newborn's likely death, and parents' worries and concerns.

6. Coordinated, consistent, and documented

- a. Use clear, unambiguous language
- b. Document parents' goals of care
- c. A contingency advance care plan/birth plan is an important communication tool
- d. Communications and documentation about the fetal/neonatal diagnosis, birth plan, and bereavement support should be shared with the entire health care team and follow up providers. Goals of care and treatment plans should be consistent across providers and settings.
- e. Develop medical records tools to share information
 - i. Ensure that the advance care plan/birth plan is easily accessible however and wherever the pregnant woman accesses health care.
- f. Plans for obtaining further testing after birth and/or death are specified
- g. Handling of the body after death including possible autopsy and disposition of the body are noted
- h. Perinatal bereavement services coordinate well with perinatal palliative care providers

7. Informed, ethical, and nonjudgmental

- a. Support shared decision making after inquiring who the decision makers are (in some cultures, it is not the parents)
- b. Good ethics starts with good facts
 - i. Ethically permissible treatment options should be discussed with the parents and a contingency birth plan developed using shared decision making
 - ii. Parents should be informed when there are inadequate data to establish a treatment plan other than routine care
- c. Be accepting of ethically appropriate treatment choices even if they are not what you would choose.
- d. Bereavement may be less likely to be complicated if parents feel confident that the decisions made were in the best interest of the mother/fetus/newborn.

8. Nimble/flexible

- a. Prior to birth, and confirmation of the diagnosis and condition of the newborn, the advance care plan/ birth plan and bereavement support plan are amenable to change based on further information and parents' preferences

9. Memorable

- a. Support memory making and retaining mementos
- b. Optimize time parents can spend with their newborn
- c. Parents frequently prefer to hold their dying newborn and should be supported if this is their preference.
- d. Parents generally report that bereavement support is aided by mementoes. Consider:
 - i. Photography
 - ii. Hand/footprints
 - iii. Hand/foot castings
 - iv. Snips of hair
 - v. Family visits
 - vi. Religious or cultural rituals
- e. Some programs provide an object, such as a teddy bear, for the mother to hold on discharge so there will be no empty arms

10. Sustained

- a. Bereavement support should be initiated soon after diagnosis of a possible fetal/neonatal life- limiting condition and continue at least for a year after death of the fetus/newborn.

What are the key components of successful bereavement programs?

- Administrative and financial support
- Leadership: this is a navigator; frequently a nurse or social worker, who supports the health care team and addresses the needs of the family
- Education: The depth of education may be linked to the frequency with which the staff deal with fetal or neonatal death. Adult ER or surgical ICU settings may experience perinatal bereavement needs less frequently than a high-risk OB perinatal service or neonatal ICU. Certainly, perinatal bereavement should be included in OB, nursery, and NICU staff education.
- Support of the staff: health care personnel also grieve
- Support of the families that is individualized, continuous, and coordinated. A preliminary birth plan can help the family participate in decision making and feel that they have some sense of control.

Fetal or neonatal death is a life-changing event for parents. Appropriate bereavement support can minimize the trauma and grief. All personnel dealing with such parents should have appropriate education and training. Where perinatal death is more frequent, there should be personnel specializing in perinatal bereavement available.

Resources

Boyle FM, Horey D, Middleton PF, Flenady V. Clinical practice guidelines for perinatal bereavement care – An overview. *Women Birth*. 2020 Mar;33(2):107-110. doi: 10.1016/j.wombi.2019.01.008. Succinct summary of effective perinatal bereavement care from the Perinatal Society of Australia and New Zealand.

Kobler K, Limbo R. Making a case: Creating a perinatal palliative care service using a perinatal bereavement program model. *J Perinat Neonatal Nurs*. 2011 Jan-Mar;25(1):32-41

Obst KL, Oxlad M, Due C, Middleton P. Factors contributing to men's grief following pregnancy loss and neonatal death: Further development of an emerging model in an Australian sample. *BMC Pregnancy Childbirth*. 2021 Jan 7;21(1):29. doi: 10.1186/s12884-020-03514-6.

Pector EA. Views of bereaved multiple-birth parents on life support decisions, the dying process, and discussions surrounding death *J Perinatol*. 2004 Jan;24(1):4-10. doi: 10.1038/sj.jp.7211001.

Ramirez FD, et al. Professional bereavement photography in the setting of perinatal loss: A qualitative analysis. *Glob Pediatr Health*. 2019 Jun 13;6:2333794X19854941. PMID: 31236429

Steen SE, Raising the bar: Development of a perinatal bereavement programme. *Int J Palliat Nurs* 2019 Dec 2;25(12):578-586

Valenzuela CP, Gregory ECW, Martin JA, Decline in perinatal mortality in the United States, 2017–2019. *NCHS Data Brief No. 429*, January 2022

Weaver MS, Jurgens A, Neumann ML, Schalley SM, Kellas JK, Navaneethan H, Tullis J. Actual solidarity through virtual support: A pilot descriptive study of an online support group for bereaved parents. *J Palliat Med*. 2021 Aug;24(8):1161-1166. doi: 10.1089/jpm.2020.0617. Epub 2021 Jan 6. This does not pertain exclusively to perinatal bereavement but provides an interesting model for after discharge support.

Grief and Bereavement Support for Underserved Communities Around the World

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Introduction

The death of a loved one is one of the most challenging experiences we face in our lives and the death of a child is particularly devastating.^{1,2} The surviving parents must navigate not only the grief of their child's death, but also the loss of the hopes and dreams for their child's future. This grief can have profound impacts on the health and well-being of surviving parents. After the death of a child, parents are at higher risks for anxiety, depression, post-traumatic stress disorder (PTSD), and psychiatric admission, than parents who have not experienced the death of a child.^{3,4,5} Childhood death, affects not only the psychological wellbeing of parents but may also impact the physical wellbeing of parents. This includes poorer health-related quality of life, increased cardiac morbidity, and increased mortality of bereaved parents as compared to non-bereaved parents.^{6,7,8,9} Because of these adverse health impacts, it is critical to provide support for these grieving parents.

One of the challenges, though, is identifying the best ways to support parents after the death of a child. There are a host of interventions that have been studied to assist bereaved parents. These include pharmacotherapy, support groups and counseling, a variety of psychotherapy modalities (cognitive-behavioral therapy [CBT], psychodynamic, psychoanalytical, and interpersonal therapies), along with systems-oriented therapies, among others.^{10,11,12}

However, most of these studies have been performed in high-income countries (HICs) amongst mothers. One study showed that 75% of parents involved in pediatric palliative care (PPC) research are mothers, the majority being white mothers.¹³ Therefore we may not have a full understanding of the grief and bereavement experience of fathers or how to best support them after the death of a child. Also, we recognize that with the incredible amount of diversity in cultures, grieving practices, and mourning rituals around the world, the current literature is insufficient when considering interventions in low- and middle-income countries (LMICs).¹⁴ Therefore, we must consider how we can better support fathers and parents who reside in LMICs. Only in this way can we truly capture the global need of grief and bereavement support for parents after the death of a child.

Grief and Bereavement in Fathers

While not considered an underrepresented group in the larger community, fathers' voices are not as prominent in the grief and bereavement literature as compared to mothers. Historically, comparisons between mothers and fathers suggested briefer and less intense grief reactions in fathers.^{15,16,17} Over the centuries in Western cultures men have had social expectations on them to be problem solvers and to not express emotions after difficult events in their life. These cultural perceptions of masculinity may have influenced how fathers experienced the death of their child.

We recently performed a systematic review evaluating the experience of grief in fathers after the death of a child.¹⁸ We focused on recent studies as the sociocultural role of fathers has evolved over the last several decades, to see if the bereavement of fathers was consistent with the previous literature. What we found was that fathers continued to grieve in isolation. Several studies showed that fathers attempted to avoid discussing their feelings after the death of a child, as opposed to more open channels of communications for mothers.^{19,20} This was deliberate choice by most fathers as they often tried to deflect attention to ensuring support to their partners. However, fathers did report how valuable it was when they were willing to open up and discuss their experience with others.¹⁹ Another critical finding was that fathers were much more likely to work throughout the child's illness and return to work sooner than their partner after the death of their child.²¹ These fathers used goal-oriented tasks at work and at home as distraction techniques, which for some fathers was helpful. For many fathers though, these efforts did not result in the same satisfaction or fulfillment prior to their child's illness and death and these fathers wished they worked less and spent more time with their child.²²

Finally, while we found that the grief intensity of fathers was less than that of mothers, the definition of grief intensity was poorly defined in the literature. Grief intensity was defined with many features being outwards expressions of grief. This may not perfectly grasp the grief experience of fathers and their gendered coping mechanisms of stoicism, isolation, and work. Additionally, while this grief intensity was higher in mothers it diminished over time it remained persistent in fathers.²³ We hypothesized that for some fathers these gendered coping mechanisms may not be sufficient for grieving over time. The disparity in paternal participation in PPC research persisted though with only 31% of the participants in the studies evaluated for our systematic review being fathers.¹⁸ More work is needed including more inclusive definitions of grief intensity to better understand paternal bereavement and to better support fathers on their grief journey.

Grief and Bereavement in LMICs

Another area in which there is need for improvement is providing grief and bereavement support for parents who live in LMICs. Most of the research understanding grief and bereavement in parents and interventions after the death of a child have predominantly been published from North America and Western Europe. However, this may not be adequate in understanding the global need of parental grief and bereavement after the death of a child. This literature may not consider the varied cultural, religious, and socioeconomic diversity that exists globally.²⁴ For example, one comparative study between bereavement counselors' experiences in Northern Ireland and Uganda showed there were significant differences in the grief experience after the death of a child.²⁵ Those researchers found the individualistic culture and approach to bereavement in Northern Ireland contrasted to the communal, collective experience in Uganda. These findings emphasize how important it is to understand the unique contexts in which bereaved families live and how that influences their capacity to find meaning after the death of their child.

Additionally, *The Global Atlas of Palliative Care at the End of Life* demonstrated that almost 98% of the global PPC need occurs in LMICs.²⁶ However, despite this need only 35% of countries globally have PPC services available.²⁷ For those that do have PPC provision, grief and bereavement support was the least available²⁸ and the service healthcare professionals feel the most uncomfortable providing for their patients' families.^{29,30} Therefore much more work is needed, to first understand the grief and bereavement experience of parents after the death of a child in LMICs, but then to identify interventions to improve capacity and training in grief and bereavement support for healthcare professionals.

A recent review of the literature has highlighted the current work in studying grief and bereavement in parents in LMICs.¹⁴ The most robust efforts have been done surrounding perinatal death. Over 30 studies evaluated the experience of death in the perinatal period with most studies being qualitative in nature. Many of the themes identified in these studies revolved around community support versus blame and stigmatization, health system barriers impeding respectful care and ensuring access to culturally appropriate psychological care, and that women want individualized support about future pregnancies.³¹

Very few studies looked at potential interventions for bereaved parents in resource-limited settings. One intervention that was highlighted, known as the nine-cell bereavement tool,^{32,33} looks at the experiences of the bereaved parent and what they outwardly expressed versus felt, as compared to what is culturally allowed/expected. This tool has been implemented in several countries globally with follow-up interviews with participants who stated they learned the importance of culture on the grief experience as well as the importance of a bereaved parent discussing their grief with others.^{32,33}

Conclusion:

The death of a child is one of the toughest things a parent may ever experience in their life. This loss may have a dramatic psychological and physical impact on a parent. There is a great amount of work looking into how to best support these parents as there is now a whole range of support services including group sessions, counseling, psychotherapy, pharmacotherapy, and systems-based approaches. However, most of the research performed on these interventions have been small, qualitative studies and further work is needed to demonstrate efficacy. Additionally, these studies have been done on a very narrow population, particularly mothers in HIC. There have been growing efforts to expand that population, including fathers, and experiences of parents in LMICs. Other communities not discussed in this article but are important to consider as well are underrepresented and marginalized communities within HICs. More concerted efforts to be inclusive in grief and bereavement research are critical as we recognize the unique experience of parental grief and how that experience is influenced by a host of factors including the social, spiritual, cultural, and economic factors the parent faces. Through a more expansive view of grief and bereavement on a global scale we can better understand how to best support all parents as they navigate that difficult journey.

References:

1. Chambers HM CF, Flenady V. Support for women/families after perinatal death. *Cochrane Database of Systematic Reviews*. 1998(2).
2. Sanders C. A comparison of adult bereavement in the death of a spouse, child and parent. *Omega* (Westport). 1979;10(4):303-322.

3. Kreicbergs, U. et al. Talking about death with children who have severe malignant disease. *N Engl J Med* 2004, 351, 1175–1186.
4. Kreicbergs, U. et al. Parental grief after losing a child to cancer: Impact of professional and social support on long-term outcomes. *J Clin Oncol* 2007 25(22), 3307–3312.
5. Li, J. et al. Hospitalization for mental illness among parents after the death of a child. *N Engl J Med* 2005, 352(12), 1190–1196.
6. Li, J. et al. Myocardial infarction in parents who lost a child: A nationwide prospective cohort study in Denmark. *Circulation*. 2002, 106(13), 1634–1639.
7. Song, J. et al. Long-term effects of child death on parents' health-related quality of life: A dyadic analysis. *Family Relat.* 2010, 59, 269–282.
8. Youngblut, J. M. et al. Parent health and functioning 13 months after infant or child NICU/PICU death. *Pediatrics* 2013, 132(5), e1295–e1301.
9. Li, J. et al. Mortality in parents after death of a child in Denmark: A nationwide follow-up study. *Lancet* 2003, 361(9355), 363–367.
10. Forte, A.L.; Hill, M.; Pazder, R.; Feudtner, C. Bereavement care interventions: A systematic review. *BMC Palliat. Care* 2004, 3, 3.
11. Endo, K.; Yonemoto, N.; Yamada, M. Interventions for bereaved parents following a child's death: A systematic review. *Palliat. Med.* 2015, 29, 590–604.
12. Ainscough, T.; Fraser, L; Taylor, J.; Beresford, B.; Booth, A. Bereavement support effectiveness for parents of infants and children: A systematic review. *BMJ Support Palliat Care* 2019. E-pub ahead of print 03 October 2019
13. Macdonald ME, Chilibeck G, Affleck W, Cadell S. Gender imbalance in pediatric palliative care research samples. *Palliat Med.* 2010;24(4):435-444.
14. McNeil MJ, Namisango E, Hunt J, Powell RA, Baker JN. Grief and bereavement in parents after the death of a child in low- and middle-income countries. *Children* (Basel). 2020 May 1;7(5):39.
15. Dyregrov A. Parental reactions to the loss of an infant child: A review. *Scand J Psychol.* 1990;31:266-280.
16. Vance J, Boyle, F., Najman, J., & Thearle, J. Gender differences in parental psychological distress following perinatal death or sudden infant death syndrome. *Br J Psychiatry.* 1995;167:806-811.
17. Moriarty HJ, Carroll, R., & Cotroneo, M. Differences in bereavement reactions within couples following death of a child. *Research in Nursing & Health.* 1996;19:461-469.
18. McNeil MJ, Baker JN, Snyder I, Rosenberg AR, Kaye EC. Grief and bereavement in fathers after the death of a child: A systematic review. *Pediatrics.* 2021 Apr;147(4):e2020040386.
19. Aho AL, Tarkka MT, Astedt-Kurki P, Kaunonen M. Fathers' experience of social support after the death of a child. *Am j.* 2009;3(2):93-103.
20. Proulx M-C, Martinez A-M, Carnevale F, Legault A. Fathers' experience after the death of their child (aged 1-17 years). *Omega: Journal of Death and Dying.* 2016;73(4):308-325.
21. Alam R, Barrera M, D'Agostino N, Nicholas DB, Schneiderman G. Bereavement experiences of mothers and fathers over time after the death of a child due to cancer. *Death Stud.* 2012;36(1):1-22.
22. Caicedo C BD, Youngblut JM, Dankanich J. Parents' wishes for what they had or had not done and their coping after their infant's or child's neonatal intensive care unit/pediatric intensive care unit/emergency department death. *J Hosp Palliat Nurs.* 2019;21(4):333-343.

23. Youngblut JM, Brooten D, Glaze J, Promise T, Yoo C. Parent grief 1-13 months after death in neonatal and pediatric intensive care units. *Journal of Loss & Trauma*. 2017;22(1):77-96.
24. Papadatou, D. Childhood death and bereavement across cultures. In *Death and bereavement across cultures*, 2nd ed; Parkes, C., Laungani, P., Young, B., Eds.; Routledge: New York, NY, USA, 2015; pp. 151-165.
25. Montgomery, L.; Owen-Pugh, V. Bereavement counselling in Uganda and Northern Ireland: A comparison. *Br. J. Guid. Couns*. 2017, 46, 91-103.
26. Connor, S.R.; Sepulveda Bermedo, M.C. *Global atlas of palliative care at the end of life*. Second Edition. Worldwide Palliative Care Alliance: London, UK, 2020.
27. Downing, J.; Powell, R.A.; Marston, J.; Huwa, C.; Chandra, L.; Garchakova, A.; Harding, R. Children's palliative care in low-and middle-income countries. *Arch. Dis. Child*. 2015, 101, 85-90.
28. Delgado, E.; Barfield, R.C.; Baker, J.N.; Hinds, P.S.; Yang, J.; Nambayan, A.; Quintana, Y.; Kane, J.R. Availability of palliative care services for children with cancer in economically diverse regions of the world. *Eur. J. Cancer* 2010, 46, 2260-2266.
29. Ehrlich BS, Movsisyan N, Batmunkh T, Kumirova E, Borisevich MV, Kirgizov K, Graetz DE, McNeil MJ, Yakimkova T, Vinitzky A, Ferrara G, Li C, Lu Z, Kaye EC, Baker JN, Agulnik A; ADAPT Research Group. A multicountry assessment in Eurasia: Alignment of physician perspectives on palliative care integration in pediatric oncology with World Health Organization guidelines. *Cancer*. 2020 Aug 15;126(16):3777-3787.
30. McNeil MJ, Ehrlich BS, Wang H, Vedaraju Y, Bustamante M, Dussel V, Friedrich P, Garcia Quintero X, Gillipelli SR, Gomez Garcia W, Graetz DE, Kaye EC, Metzger ML, Sabato Danon CV, Devidas M, Baker JN, Agulnik A; Assessing Doctors' Attitudes on Palliative Treatment (ADAPT) Latin America Study Group. Physician perceptions of palliative care for children with cancer in Latin America. *JAMA Netw Open*. 2022 Mar 1;5(3):e221245.
31. Shakespeare, C.; Merriel, A.; Bakhbakhi, D.; Baneszova, R.; Barnard, K.; Lynch, M.; Storey, C.; Belncowe, H.; Boyle, F.; Flenady, V.; et al.. Parents' and healthcare professionals' experiences of care after stillbirth in low- and middle-income countries: A systematic review and meta-summary. *BJOG* 2019, 126, 12-21.
32. Hunt, J. The nine-cell bereavement table. *Bereave. Care* 2002, 21, 40-41.
33. Hunt, J.; Andrew, G.; Weitz, P. Improving support for bereaved people within their communities. *Bereave. Care* 2007, 26, 26-29.

“We Need Support Too”: Recognising, Understanding and Supporting Men Through Their Grief After the Death of a Baby

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“Losing my children has changed me in profound ways...There will always be two holes in me, and I often wonder how different it would have been if I had more support at the time and over the years since.”

– Father of two babies lost to late-term miscarriage

For millions of families each year, the death of their baby prior to, during, or shortly after birth is a devastating reality. Such deaths represent a unique form of grief. In previous research, bereaved parents have described intense feelings of shock, sadness, disbelief, and yearning for their hopes and dreams for raising a child.^{1,2} However, in addition to these typical and expected responses, the death of an unborn, stillborn, or newborn baby can be further complicated by feelings of ambiguity surrounding parenthood,³ experiences of stigma,⁴ a lack of open social acknowledgement for the life of the baby, and uncertainty regarding shared social rules for how to mourn such a loss.⁵ When a medical termination of pregnancy for life-limiting or non-viable anomalies (TOPFA) occurs, parents can also face additional stigma and both perceived and overt judgement from others due to ongoing contentions in many countries surrounding abortion.^{6,7,8}

In recent years, however, there has been increasing social recognition for parents' grief after the death of a baby, as well as a growing body of empirical research exploring parents' healthcare and social support needs. Best practice bereavement care guidelines have also been developed in many countries to guide healthcare professionals in caring for parents in the hospital setting and beyond (e.g.,^{8,9,10}). While these developments have been undoubtedly important and influential in improving parents' experiences of grief and care, men's experiences of grief and support after the death of a baby have historically been under-explored; particularly when compared to the large body of research on women's experiences.

In acknowledging this important gap, our research team recently undertook a mixed methods program of research to comprehensively explore men's experiences of grief and support after pregnancy loss and neonatal death. Comprising a systematic review,¹¹ a nationwide Australian survey,^{12,13} and follow-up qualitative interviews focusing on men's experiences following TOPFA¹⁴ and neonatal death,^{15,16} we triangulated findings from across the studies to inform a conceptual model of how men grieve, factors that contribute to men's grief, and suggestions for how healthcare services, systems and policies can best support men in future.

How do men grieve?

Across our studies, men's grief was a highly individualised experience, with a wide range of grief scores on psychometric scales, as well as descriptions of grief varying from "overwhelming" and "intense" to focusing on "empathy for [my wife]." However, contrary to early studies in the field that suggested men generally display lower levels of grief than women (and are therefore less affected by loss),^{17,18,19} in our nationwide survey men's average grief scores were above the cut-off for what can be considered a high degree of grief—regardless of loss type.

Doka and Martin²⁰ described styles of grief ranging on a continuum from intuitive (emotion-focused including talking, crying, and seeking support) to instrumental (activity and problem-solving focused). In our research, many men coped with their grief through activities including returning to work, 'keeping busy' and engaging in hobbies. However, many also described intuitive grief styles, and/or recognised a need to balance the use of distraction-focused coping with emotional expression and processing of grief.

Many men described being preoccupied with their (female) partner's needs immediately following their loss given the clearer physical health implications of pregnancy and birth. This aligned with previous research describing men's primary role as a 'supporter' to their partner and family following a loss.^{21,22,23} Importantly, however, while early research had often conceptualised this role as detrimental to men's ability to process their own grief, our studies suggested potential benefits of being a 'supporter,' including giving men a clear focus/purpose in the immediate aftermath of the loss. Although where this role took precedence over men's own grief and needs, it could negatively impact upon grief. In addition, many men described experiencing a 'delayed' grief response as a consequence of focusing on supporting, with their own emotional needs surfacing only after they perceived their partner's grief had begun to subside. One interview participant described:

"And so [wife] went from needing my help to—well, not not needing my help, but, yeah, needing support, to being okay. And I kind of felt like I got left behind a little bit [...] I hadn't taken any of that time to actually understand and process what had happened for myself."

Men who have experienced a TOPFA have been substantially under-represented in previous research.²⁴ In our interviews with these men, they expressed unique challenges associated with this loss type including complexities surrounding decision making, and for some, a perceived need to conceal the type of loss they experienced to avoid judgement from others. One participant said:

"...not a lot of people knew that it was a medical termination like of our choice, they just knew that it was a miscarriage. And it was very select people, only because we didn't want people's opinions of it."

What factors impact men's grief?

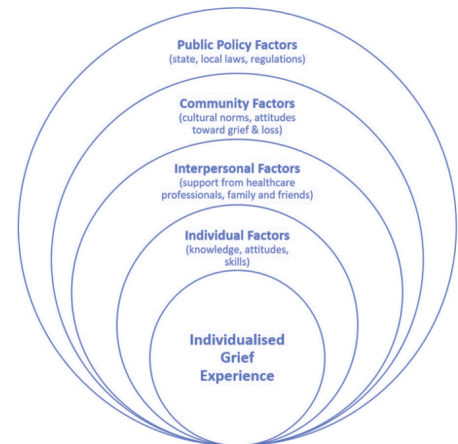
In our systematic review we proposed a Socio-Ecological Model of Men's Grief¹¹ to describe the various levels of inter-related factors that appeared to influence the intensity of men's grief (see Figure 1). In our nationwide survey, we tested the relationships between men's grief and these various factors. Findings indicated that at the individual level, for example, the depth of men's attachment to their babies was strongly related to grief intensity. At the interpersonal level, a good quality relationship with their partner and higher levels of acknowledgement of men's grief from family and friends was associated with reduced grief scores. At the community level, experiences of disenfranchisement due to a lack of social recognition for their babies, as well as masculine role expectations

including a need to be 'strong' and hide emotional expressions, were associated with worsened grief. Finally, at the system/policy level, a focus on woman-centred care in the hospital had the potential to lead to feelings of isolation which could complicate grief, and a lack of opportunities to take workplace paternal and/or bereavement leave meant many men returned to work soon after their loss. While an early return to work was helpful for some men, others felt they returned to work "too soon," leading to burnout, stress, and decreased productivity.¹³

Figure 1. Socio-Ecological Model of Men's Grief

Adapted from "Men's grief following pregnancy loss and neonatal loss: A systematic review and emerging theoretical model." by K.L. Obst, C. Due, M. Oxlad, and P. Middleton, 2020, BMC Pregnancy and Childbirth, 20, p.12. Copyright 2020 by the Authors.

Factors impacting grief also varied depending on grief style. Findings indicated that intuitive grievers may benefit from increased levels of hospital support and inclusion, whereas instrumental grievers may benefit from increased social/peer support and partner acknowledgement for men's grief.¹²



What support do men want and need?

While participants in no way wanted to detract from their (female) partner's health and needs, a focus primarily on women's health in the hospital environment represented a substantial barrier for many men in recognising their own needs, and seeking and receiving support for their grief. In this setting, men many described a struggle to find their fit where they existed as 'neither patient, nor visitor.'¹⁴

One participant described:

"In the hospital, I was certainly very much acknowledged in the room, I wasn't just an outsider [...] but it was very much geared towards my partner and her experience. Only really the one pamphlet about men and a support group, which I really wasn't keen in that moment, or any moment following, to go and actually join."

Similarly, while mental health assessments for mothers are standard practice in many perinatal health settings, some participants in our research were concerned that their own history of mental health difficulties was not formally assessed prior to discharge. Although many participants reported that they received standard informational brochures on grief and general supports available in the community, they also expressed a need for tailored information about how to both support their partner and find support for themselves. Some suggested that sharing of this information could be facilitated by nursing/midwifery staff or a grief support person taking men aside and "talk[ing] to them in their own language". **Another participant shared:**

"the day after, they sent two counsellors in to speak to us together [... but] she spoke to [wife]. Unless I spoke up and said something in response to a question, she looked at [wife] [...] So, I'm sitting there, and all I'm hearing is: I have to look after her. I have to support her. I have to make sure she's okay. I have to be strong enough to bear the weight of my own grief, as well as support the weight of my wife's [grief]"

Finally, due to societal expectations that men should 'support' their partners, many felt they were therefore less likely to seek out services for themselves. In this context, there appeared to be a need for active and direct follow-

up from healthcare professionals to provide men with an opportunity to acknowledge their own needs and be reminded of support available to them.

"There's this sort of, societal thing, this pressure to be the bloke, be the dad [...] I didn't want to go and look for help after losing [baby] [...] I needed someone to check on me, to push me to do something. And, that can't be my wife. Because my wife is in the middle of it too."

Practice recommendations: hospitals and bereavement care

While not all men will require formal support through their grief after the death of their baby, there is a pressing need to reduce existing barriers to accessing care for men, particularly at the health systems level. No matter the type of loss, it is important men receive acknowledgement and validation of their grief, as well as active inclusion throughout all stages of healthcare engagement.

A number of key recommendations for hospitals and perinatal healthcare settings arose from our program of research. Firstly, that all fathers/partners leave the hospital with information about men's grief and contact details for 24-hour follow-up support, and receive brief mental health screening for early identification of risk. Where possible, information on supports should be tailored to be men-specific and relevant to geographic location. Secondly, where possible and appropriate, couples/family units should attend post-loss healthcare meetings together; this may require flexibility regarding time and/or place to accommodate parents who may have returned to work. Finally, all fathers/partners should receive at least one individual follow-up call or visit from an appropriately skilled health care professional after their partner is discharged from hospital, including additional follow-up in the weeks/months following to account for potentially delayed grief presentations.

While there are recognised challenges for healthcare professionals to engage with men in busy perinatal healthcare settings,^{25,26} participants also highlighted that small efforts to promote inclusion of men can have a lasting, positive impact on their ability to acknowledge and deal with their grief. One father shared:

"...they kept on saying to me [...] make sure you keep talking about this and don't sit there and feel as though you can't say anything [...] because you're part of this process. It's not just your wife who's going through this [...] you know, are you alright, are you okay? [...] quite direct and ensured that they'd spoken to me [...] I didn't want to take away from [wife], but I think what they did really helped."

Overall, it was clear from this program of research that support and recognition received in the hospital or healthcare setting where the loss took place precipitated men's ongoing and long-term experiences of grief and access to ongoing support in the community. Adequate acknowledgement for their grief and proactive support from healthcare professionals will not only ease the burden of grief for men, but could have a powerful influence on the health and wellbeing of all families facing the loss of their precious babies.

References

1. Cacciatore J. Psychological effects of stillbirth. *Semin Fetal Neonatal Med.* 2013;18(2):76–82.
2. McCreight BS. Perinatal loss: a qualitative study in Northern Ireland. *OMEGA: Journal of Death and Dying.* 2008;57(1):1–19.

3. Lang A, Fleischer AR, Duhamel F, Sword W, Gilbert KR, Corsini-Munt S. Perinatal loss and parental grief: The challenge of ambiguity and disenfranchised grief. *OMEGA: Journal of Death and Dying*. 2011;63(2):183–96.
4. Pollock D, Pearson E, Cooper M, Ziaian T, Foord C, Warland J. Voices of the unheard: A qualitative survey exploring bereaved parents' experiences of stillbirth stigma. *Women Birth*. 2019;33(2):165–74.
5. Doka KJ. Disenfranchised grief. *Bereavement Care*. 1999;18(3):37–9.
6. France EF, Hunt K, Ziebland S, Wyke S. What parents say about disclosing the end of their pregnancy due to fetal abnormality. *Midwifery*. 2013;29(1):24–32. <https://doi.org/10.1016/j.midw.2011.10.006>
7. Hanschmidt F, Trembl J, Klingner J, Stepan H, Kersting A. Stigma in the context of pregnancy termination after diagnosis of fetal anomaly: Associations with grief, trauma, and depression. *Archives of Women's Mental Health*. 2018;21(4):391–399. <https://doi.org/10.1007/s00737-017-0807-9>
8. Boyle FM, Horey D, Middleton PF, Flenady V. Clinical practice guidelines for perinatal bereavement care—An overview. *Women and Birth*. 2020;33(2):107–110. <https://doi.org/10.1016/j.wombi.2019.01.008>
9. National Bereavement Care Pathway. (2020). The five bereavement care pathways. Sands (Stillbirth & Neonatal Death Charity). <https://nbcpathway.org.uk/>
10. Health Service Executive. (2016). National standards for bereavement care following pregnancy loss and perinatal death. *Feidhmeannacht na Seirbhíse Sláinte*. p. 82. <https://www.hse.ie/eng/services/list/3/maternity/bereavement-care/>
11. Obst KL, Due C, Oxlad M, Middleton P. Men's grief following pregnancy loss and neonatal loss: A systematic review and emerging theoretical model. *BMC Pregnancy and Childbirth*, 2020;20(1):11-17. <https://doi.org/10.1186/s12884-019-2677-9>
12. Obst K, Oxlad M, Due C, Middleton P. (2021). Factors contributing to men's grief following pregnancy loss and neonatal death: Further development of an emerging model in an Australian sample. *BMC Pregnancy and Childbirth*. 2021;21(1):29-1-29-16. <https://doi.org/10.1186/s12884-020-03514-6>
13. Obst KL, Due C, Oxlad M, Middleton P. Australian men's experiences of leave provisions and workplace support following pregnancy loss or neonatal death. *Community, Work and Family*. 2020: 1-12. <https://doi.org/10.1080/13668803.2020.1823319>
14. Obst K, Due C, Oxlad M, Middleton P. Men's experiences and need for targeted support after termination of pregnancy for foetal anomaly: A qualitative study. *Journal of Clinical Nursing*. 2021;30(17-18), 2718-2731. <https://doi.org/10.1111/jocn.15786>
15. Azeez S, Obst KL, Oxlad M, Due C, Middleton P. Australian fathers' experiences of support following neonatal death: A need for better access to diverse support options. *Journal of Perinatology*. 2021;41(12):2722-2729. <https://doi.org/10.1038/s41372-021-01210-7>
16. Azeez S, Obst KL, Due C, Oxlad M, Middleton P. Overwhelming and unjust: A qualitative study of fathers' experiences of grief following neonatal death. *Death Studies*. 2022: 12 pages. <https://doi.org/10.1080/07481187.2022.2030431>
17. Alderman L, Chisholm J, Denmark F, Salbod S. Bereavement and stress of a miscarriage: As it affects the couple. *Omega: Journal of Death and Dying*. 1998;37(4):317–27. <https://doi.org/10.2190/DQNG-PFAM-7V00-52F3>
18. Conway K, Russell G. Couples' grief and experience of support in the aftermath of miscarriage. *British Journal of Medical Psychology*. 2000;73(4):531–45. <https://doi.org/10.1348/000711200160714>
19. Cope H, Garrett ME, Gregory S, Ashley-Koch A. Pregnancy continuation and organizational religious activity following prenatal diagnosis of a lethal fetal defect are associated with improved psychological outcome.

- Prenatal Diagnosis. 2015;35(8):761–8. <https://doi.org/10.1002/pd.4603>
20. Doka KJ, Martin T. Grieving styles: Gender and grief. *Grief Matters: The Australian Journal of Grief and Bereavement*. 2011;14(2):42–5.
 21. Bonnette S, Broom A. On grief, fathering and the male role in men's accounts of stillbirth. *Journal of Sociology*. 2011;48(3):248–65. <https://doi.org/10.1177/1440783311413485>
 22. McCreight BS. A grief ignored: narratives of pregnancy loss from a male perspective. *Sociology of Health and Illness*. 2004;26(3):326–50. <https://doi.org/10.1111/j.1467-9566.2004.00393.x>
 23. Rinehart MS, Kiselica MS. Helping men with the trauma of miscarriage. *Psychother Theory Res Pract Train*. 2010;47(3):228–95. <https://doi.org/10.1037/a0021160>
 24. Hodgson J, Pitt P, Metcalfe S, Halliday J, Menezes M, Fisher J, Hickerton C, Petersen K, McClaren B. Experiences of prenatal diagnosis and decision-making about termination of pregnancy: A qualitative study. *Australian and New Zealand Journal of Obstetrics and Gynaecology*. 2016;56(6):605–613. <https://doi.org/10.1111/ajo.12501>
 25. Alio AP, Bond MJ, Padilla YC, Heidelbaugh JJ, Lu M, Parker WJ. Addressing policy barriers to paternal involvement during pregnancy. *Maternal and Child Health Journal*. 2011;15(4):425–430. <https://doi.org/10.1007/s10995-011-0781-1>
 26. Firouzan V, Noroozi M, Farajzadegan Z, Mirghafourvand M. (2019). Barriers to men's participation in perinatal care: A qualitative study in Iran. *BMC Pregnancy and Childbirth*. 2019;19(1):45. <https://doi.org/10.1186/s12884-019-2201-2>

Readers' Corner

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Davies B, Steele R, Baird J. *Pediatric Palliative Care: A Model for Exemplary Practice*. Taylor & Francis; 2021

Summary: This is a well written, easy to read textbook geared toward optimizing the pediatric palliative care (PPC) provider relationship with the child/adolescent and their family by arming providers with the tools to become "exemplary pediatric health-care providers" (EPP). There is a gap in professional training concerning the principles and benefits of effective patient and family communication and relationship building. The assumption is that optimal hopeful and supportive communication will avoid missed opportunities to discuss care and prognosis and lead to not only improved satisfaction on both sides, but improved patient and family outcomes.

Who: All providers who interact with children with medical complexity and families should read this book. It will reinforce positive practices and introduce strategies to further improve communications and hence outcomes.

What is special about this book?

- **Approach:** This book focuses on the application of the knowledge that is taught in professional school in order to optimize outcomes. Optimal communication is central to optimal outcomes. Most of the examples focus on the parents. I wish that they had commented more on exemplary communications with the children. The windmill metaphor is used to show the interactions of the various participants and components. While I occasionally found this a bit distracting, it was helpful in seeing interactions between the components. This approach is grounded in research. The practical examples are very helpful in providing a roadmap for professional improvement in communication and building relationships.
- **Target readers:** All the PPC professionals who interact with the child/adolescent and family should read this book. We can all learn how to communicate more effectively and supportively.
- **Impact:** By communicating and listening effectively, providers are better able to get needed information and respectfully provide culturally-appropriate patient and family interventions that support the child and family. By avoiding misunderstandings, missed opportunities, and decisions based on inadequate information, improved communications enhance the outcomes of the child/adolescent, the parents and extended family, and the health care providers. Near the end the authors note that when the conceptual model was presented at conferences feedback included "Your model is really more than a model for dealing with parents of an ill child; it is a model for living, for all of us."
- **Exercises:** At the end of most of the chapters are "Questions for Consideration." These questions help providers assess themselves and others and see how they can improve. Suggestions for enhancing these communication and relationship building skills in new team members are particularly helpful.

Where and how can I apply this information? A provider can apply this information in every patient and family interaction. I found this book more insightful and helpful than any other PPC text that I have ever read, as it not only told me what I needed to know and do but, more importantly, how I could obtain or enhance the skills to optimize patient, family, and provider outcomes. Reviewing the chapter on institutional factors may give providers tools with which to interact positively with their organization to optimize care.

When should I get this book? Now! It is widely available for under \$40 in the paperback version.

From the publishers: *Pediatric Palliative Care: A Model for Exemplary Practice* lays out a road map for healthcare providers interested in optimizing care for seriously ill children and their families.

Grounded in clinical practice and the study of positive rather than problematic encounters between providers and parents, the book presents an evidence-based model of exemplary interaction. Chapters offer a clear understanding of the complex, holistic process of interaction between providers and parents, as well as the personal and professional knowledge and skills needed to interact in optimal ways.

This is a one-of-a-kind guidebook for healthcare providers interested in (re)discovering how to maximize positive outcomes for both families and providers. It's also a valuable source of inspiration for educators, supervisors, and hospital administrators who want to facilitate personal and professional development and create supportive environments for students, providers, seriously ill children, and their families.

BY THE WAY: THERE IS NOW A SECOND EDITION OF INTERDISCIPLINARY PEDIATRIC PALLIATIVE CARE, EDITED BY JOANNE WOLFE, PAMELA S. HINDS, & BARBARA SOURKES PUBLISHED IN MARCH 2022. THE PREVIOUS EDITION WAS FROM 2011. HOPEFULLY A LESS EXPENSIVE SOFTCOVER EDITION WILL APPEAR SOON.

Items of Interest

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

1. NHPCO Palliative Care Online Resources:

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

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

Palliative Care Programs and Professionals

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

[Individual Palliative Care Membership](#)

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

2. Pediatric Hospice and Palliative Care Resources:

- **CaringInfo**, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. www.caringinfo.org
- [NHPCO's Palliative Care Resource Series](#) includes pediatric palliative resources like:
 - Communication Between Parents and Health Care Professionals Enhances
 - Satisfaction Among Parents of the Children with Severe Spinal Muscular
 - Atrophy
 - Consideration for Complex Pediatric Palliative Care Discharges
 - Songs of the Dying: The Case for Music Therapy in Pediatric Palliative and
 - Hospice Care
 - Nonpharmacological Pain Management for Children
 - Sibling Grief
 - Pediatric Pain Management Strategies
 - Communicating with a Child Experiencing the Death of a Loved One: Developmental Considerations

3. Trends in Pediatric Palliative Care Research

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

4. Pediatric Resource on Medication Coverage

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

5. Pediatric Hospice and Palliative Care Training:

- [Upcoming Webinars](#) provided by the Pediatric Care Coalition:
- June 23: Understanding the Lived Experience of Siblings of Children with Significant Neurological Impairment
- July 19: Creating Legacy: Developing End of Life Protocols Following the Death of a Child
- August 18: Conversations Matter: pediatric Advance Care Planning (pACP) and Shared Decision Making with Adolescents Living with a Serious Illness -- The FAmily CEntered (FACE) pediatric Advance Care Planning Model

6. MyNHPCO Bereavement Community

Continue the conversation of this quarter's e-journal on NHPCO's member-only [community for Bereavement professionals](#). Professionals whose practice and focus are on bereavement care and services to hospice and palliative care patients and families are welcome to join. The community hosts bereavement discussion boards, a library of resources, and monthly chats on a range of topics, including services, networking, and idea and resource sharing.

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

We are currently discussing topics like supporting siblings, care in the community, and standards for the issues immediately before us. If you have any thoughts about these or other topics, contributors, or future issues, please contact Christy at christytork@gmail.com or Suzanne Toce at tocess@gmail.com.



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