

Bereaved Parents, Hope, and Realism

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Parents of children with serious illness often maintain hope across a child's illness journey. Historically, the conflict between parental hope and prognostic acceptance has been described as a pendulum oscillating between antithetical states of awareness. In this commentary, bereaved parents partner with interdisciplinary pediatric palliative care clinicians to discuss and challenge the conventional theory in which hope and realism exist as diametrically opposing spaces within which parents vacillate. As parents and clinicians, we offer a reconceptualized model that validates a parent's ability to experience hope and prognostic awareness simultaneously, avoiding assumptions that conflate hope as misinterpretation or denial. In our discussion, we advocate for health care professionals to consider this framework when partnering with patients and families who carry coexisting hope and prognostic awareness in the context of a child's progressive illness.

HISTORICAL FRAMEWORKS FOR HOPE: THE PENDULUM MODEL

For parents of children with serious illness, hope is a uniquely powerful mechanism that enables coping and promotes resilience.^{1,2} Parents describe hope as a life-sustaining factor,^{2,3} one that impacts decision-making processes across their child's illness journey.^{1,4} Recent data reveal parental hopes to be fluid, evolving across the illness trajectory^{5,6} and persisting in the face of critical illness and at the end of life.^{1,6,7}

In the setting of serious pediatric illness, tension exists between sustaining hope and expressing

prognostic understanding.¹ To capture this strain, the analogy of a swinging pendulum has been proposed to reflect the fluctuation between parents' persistent hope for a cure and awareness of a child's impending death.⁸ Similarly, the imagery of a pendulum also has been used to describe parents' oscillation between hoping for the best and preparing for the worst.³

Although the pendulum model accurately illustrates how a parent might experience diametrically opposed viewpoints within short time frames, this analogy has several limitations. First, this model intrinsically creates opposition between hope and prognostic awareness. Challenging this concept, parents of children with serious illness have described a phenomenon in which they balance hope and acceptance as coexisting variables rather than conflicting philosophies.¹ Second, the ball at the end of the swinging pendulum cannot exist in both spaces simultaneously. In the authors' collective experience, parents who face the imminent death of their child often describe hope and awareness as coincidental realities. Third, if the prognostic awareness side of the pendulum arc represents a true version of reality, then a parent who swings toward the side of hope, by default, becomes easily labeled as in denial or in conflict with the medically factual situation.

Within the pendulum paradigm, conceptualizing hope as either realistic or fictitious creates a false dichotomy, one that risks trapping clinicians into

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erroneous assumptions about parents' goals and wishes. Particularly at the end of life, health care professionals may misinterpret sustained hope as refusal to accept reality, resulting in needless friction between patients, families, and clinicians.⁹ Categorizing families who express hope for cure as in denial can cause significant discomfort for staff providing care to a dying child¹⁰⁻¹² as well as result in repetitive and painful disclosures of a grim prognosis to an already aware family.¹³

Moreover, clinicians who view prognostic realism and hope for a cure as mutually exclusive perspectives may feel compelled to limit prognostic information in an effort to preserve hope.¹⁴ Yet data reveal that transparent disclosure of a poor prognosis by the physician does not diminish hope.¹⁴ Ultimately, most parents remain hopeful regardless of the severity of the prognosis, and direct provision of upsetting prognostic information does not enervate parents' perceptions of hope.¹⁵ Importantly, many parents of children with advanced illness hope for a cure while simultaneously acknowledging their child's unlikely survival.^{16,17} In the authors' aggregated clinical experience, this phenomenon is prevalent and powerful; accurate recognition of the concept of simultaneous dual realities carries profound capacity for promoting resilience, whereas failure to recognize this concept may cause undue harm to families and health care staff.

BEYOND THE PENDULUM: BEREAVED PARENTS IDENTIFY THE NEED FOR A NEW CONCEPTUAL MODEL

To better understand the phenomenon of simultaneous coexistence of hope and realism, bereaved parents on the Quality of Life Steering Council at a large academic pediatric cancer center convened to review this topic.

Historically, the Quality of Life Steering Council was established to develop, promote, and expand institutional support for families of children who die after serious illness. The council is composed of bereaved parents, a grief and bereavement psychologist, pediatric palliative care clinicians, social workers, child-life specialists, and spiritual care providers. Bereaved parents on the council use their personal experiences to advocate for improvements in clinician awareness of patient and family needs across the illness course and after the death of a child.¹⁸ Parents previously have described their participation in collaborative activities to improve understanding of the patient and parent illness experience as a profoundly meaningful component to their child's legacy.^{19,20}

Bereaved parents on the steering council have personal, first-hand experience with tensions that arise when families and clinicians misinterpret one another's hopes in the setting of a child's approaching end of life. These parents wished to create a novel conceptual model to help patients with serious illness, families, and health care professionals better understand the phenomenon of simultaneously hoping for a cure and understanding prognostic gravity. This mission led to a partnership between the institutional palliative care team and the steering council to explore alternative frameworks to describe parental hope across the progressing illness trajectory.

COLLABORATIVE DEVELOPMENT OF A NOVEL MODEL

The Hear Our Parent Experiences (HOPE) subpanel of the steering council was convened, through which bereaved parents and palliative care interdisciplinary clinicians met to discuss the concept of hope versus realism in the setting of a child's progressive disease. Across iterative meetings, several central questions

were formulated to help frame these collaborative conversations: (1) What did hope mean to you during your child's illness, particularly toward the end of your child's life? (2) Did you ever feel hopeful and realistic at the same time? (3) What did that experience look or feel like to you?

Eleven bereaved parents on the steering council reflected orally on these questions in 2 face-to-face HOPE forums, and 9 parents shared their experiences in written prose with the collaborative group, with the goal of synthesizing a spectrum of parent perspectives to inform the development of fresh imagery as an alternative to the pendulum model. Two palliative care clinicians on the steering council (E.C.K. and A.K.) compiled and organized parent verbal and written responses to formulate the primary messages emerging from the forums. All participating parents and clinicians reviewed and discussed the synthesized materials to ensure that the narrative and text accurately reflected the perspectives shared by the bereaved parents. Below, we share our consensus report consolidated from the HOPE forums.

DEFINITIONS AND INFRASTRUCTURE OF HOPE

Bereaved parents identified 7 working definitions of hope in the face of a child's advancing illness and approaching end of life, which subsequently helped inform the development of a conceptual model. These definitions are presented in the exact words of the bereaved parents in Table 1. Parents further distilled their experiences into 3 salient variants of hope, also presented in Table 1: hope for a cure, hope for life beyond illness or return to normalcy, and hope for comfort or mitigation of suffering.

Collaborative reflection on the question "What did 'hope' mean to you during your child's illness, particularly toward the end of your child's life?" generated 6 unique

TABLE 1 Bereaved Parents' Definition of Hope

	Definition
Definitions of hope in the face of a child's advancing illness and approaching end of life	<p>"Hope is the antithesis of despair, not reality."</p> <p>"To be hopeful is a function of the heart and a decision of will, to be realistic is merely a function of understanding the most likely outcome."</p> <p>"Hope is a choice, it is a decision to not give up. Hope is not about outcome, it is about the fight."</p> <p>"Hope means I can be here even though here is an unthinkable place. It is hope that provides the strength that is needed to face dire circumstances."</p> <p>"Hope was my vehicle to cope. I believe that without hope in something, there is no point to anything."</p> <p>"We are living every day as if it could be [my child's] last but also as if he might live forever. That was hope.... In the darkest places of worry, sadness, and fear, there was the tiniest bit of light I would call hope."</p>
3 major themes underpinning variants of hope	
Cure	<p>"Hope that the tumor was benign.... Hope that even in the face of tumor regrowth and the end of cancer-directed therapy that somehow she would survive."</p> <p>"When he relapsed just 2 1/2 months after going home, my hope was that a bone marrow transplant would cure him."</p>
Life outside of illness or return to normalcy	<p>"During [my child's] illness, my hope was...that we would go home so he could get his driver's license, go to the prom, graduate high school, go to college, get married, have children, and live a long happy life."</p> <p>"[My child's] desire to graduate high school, have a relaxing summer vacation, and get some time in college."</p>
Comfort or no suffering	<p>"My hope was that he would not experience suffering or be afraid."</p> <p>"It was in the course of her suffering...in the middle of her limitations...that we hoped for her to be freed from it all."</p>

motifs: (1) hope as an action, (2) hope as a survival mechanism, (3) hope as validation of the "good parent" role, (4) hope as an evolving experience, (5) persistence of hope for a miracle, and (6) existence of hope at death and beyond. These concepts, enriched by stories shared by our bereaved parent coauthors, are described in Table 2.

Consolidation of parent responses to the question "Did you ever feel hopeful and realistic at the same time? What did that experience look or feel like to you?" yielded unanimity in the belief that parents facing the likely death of a child invariably experience both profound hope that their child will survive and coinciding understanding that their child will die. The parents' personal experiences with the simultaneous coexistence of hope and prognostic awareness are communicated in their own words in Table 3.

CRAFTING AN EVOCATIVE VISUAL

We met with a panel of graphic design artists to review the goals of

this collaboration using the exact language that the parents provided to guide figure development. We convened a series of 5 brainstorming sessions to discuss, deliberate, and construct different visual concepts, eventually reaching consensus on the conceptual model presented in Fig 1. In this model, a figure exists within a wind-swept circle of flowers, simultaneously watering the flowers while also cradling a flower as its petals drift away. The figure is intentionally amorphous, androgynous, ageless, and not affiliated with a particular race or ethnicity, allowing space for diversity of representation. The swirling circle is evocative of the life cycle, the flowers illustrative of the beauty and fragility inherent to life. The watering can symbolizes the good parent role²¹ and the parent's intrinsic hope to continue supporting and nurturing the child. At the same time as the parent pours life into the child, the parent also acknowledges the falling petals and gently allows the child's spirit to let go. Importantly, even as the petals fall from the hand, the

flower does not lose its wholeness nor appear any "less." Further details related to imagery conceptualization are provided in the figure legend.

AFFIRMATION OF CONCEPTUAL FRAMEWORK

Feudtner's⁷ "breadth of hopes" is embodied in the range of hopes expressed by our bereaved parent coauthors, who sought to develop a new framework to describe hope in the face of progressive illness. While discussing and codifying the proposed model, bereaved parents defined hope as essential and intrinsic to the anticipatory grief and bereavement journeys. Whether wishing for a cure, a return to normalcy, or mitigation of suffering, parents unanimously emphasized the ever-presence of hope as indispensable, not despite (or in opposition to) their realism but, rather, because of their prognostic awareness.

This consensus statement affirms the growing body of literature on parental hope in the context of serious pediatric illness, in which hope has been described as an

TABLE 2 The Infrastructure of Hope

Theme	Example
Hope as an action	“Hope is a choice, it is a decision to not give up. Hope is not about outcome, it is about the fight.” “Hope gives you the opportunity to dream and wonder about the possibility of your child beating the odds.”
Hope as a survival mechanism	“Hope means I can be here even though here is an unthinkable place.” “It was my way to cope in the moment and get through the next stage of whatever was happening.” “Without hope and faith, I don’t know how any parent can handle a child being diagnosed with cancer.” “Hope served as a bit of a survival mechanism for me in the darkest places of worry, sadness, and fear, there was the tiniest bit of light I would call hope...I can still remember how it feels in my heart. It is such a gift.”
Hope as validation of the “good parent” role	“Being human parents, who could not fathom living in a world without our child in it, we continued to pray for a miracle, and continued to believe that God could deliver one.” “I knew and completely understood what we were facing, but in hope, I was not giving up on [my child]. I could never give up on him.” “From a clinician’s standpoint, they are often wanting parents to see the reality of which way they see the dancer spinning: perhaps counterclockwise (ie, that a child is likely to die). A parent on the other hand wants to see the more natural path of clockwise (ie, the child will continue to live) because it is so ‘counter’ to think otherwise of our children.”
Hope as an evolving experience	“In regard to [my child]’s illness, especially toward the end of her life, our hope shifted. It shifted from cure, to quality.” “[The hope that my child would be healed] was like a big umbrella over the whole journey. But there were also more ‘realistic’ hopes under that big one. Hope that it wouldn’t come back. When it came back, we hoped for a chemo to kill it. When it continued to grow, we hoped for a chemo that would slow it down.” “Hope was a real rollercoaster during [my child]’s treatment... Towards the end, though, my hopes became more focused on short-term things... Once [my child] went on hospice care, my hopes mainly focused on [my child] finding peace before the end... At the very end, my hopes all changed to healing for [my child] and seeing [my child] again at the end.” “I remember one day very clearly when it hit me that we actually needed a miracle for [my child] to survive. So, of course I changed my prayers to specifically ask for that miracle.”
Persistence of hope for a miracle	“In fact, about a week before he died...we still hoped that God would intervene and do a miracle in [my child]’s body.” “I never stopped hoping for a complete and lifelong cure, even when the odds went from 85% to 5%.” “Until the very end of [my child]’s life, I remained hopeful that he would be one of the few patients that survives despite the odds and grim prognosis the doctors gave us.” “The knowledge was ‘[my child] was probably going to die,’ the ‘hope’ was he just might be the exception.”
Existence of hope at death and beyond	“Hope was present until [my child] took her last breath, and maybe even a few minutes longer—that perhaps, she would draw one more... The hope at the end of life was no different than the hope we had throughout [my child]’s journey; all that changed were the percentages of that hope being realized.” “It was in the course of her suffering...in the middle of her limitations...that we hoped for her to be freed from it all... From healing on earth to healing in heaven.” “I knew that his healing would not be physical but was still hoping that his spiritual healing would be complete.” “Since his death, I have great hope in that wonderful day when I will see my son again.”

“essential, powerful, deliberate, life-sustaining, dynamic” entity and a source of strength absolutely necessary for day-to-day survival.^{3,22,23} At first glance, the fortification of hope in the face of apparent clinical deterioration may seem paradoxical. Yet if one conceptualizes hope as life-affirming as opposed to death-denying,²⁴ then this phenomenon begins to crystalize. Hope can help create space for coping and healing, irrespective of whether the goal is cure or comfort. Importantly, reliance on hope appears not to be harmful; specifically, parental hope for a cure at the end of their child’s life has not been associated with increased depression symptoms or long-term complicated bereavement.²⁵ Rather, hope exists as

a salve, a means to ease, rather than deny, the pain.

Historically, a parent’s ability to feel hope and acknowledge reality has been described as a type of push-and-pull process or a wavering between states of awareness.^{8,26} Our bereaved parent coauthors challenge this paradigm, suggesting instead that hope and realism can coexist simultaneously rather than oscillate. One parent pointed to the optical illusion of a spinning dancer²⁷ to describe the coexistence of hope and prognostic understanding (Table 3); both truths inherently have the potential to coexist. Crucially, if a parent verbalizes hope as a means for coping or survival, this does not necessarily indicate lack of awareness

or denial, nor does it necessarily mandate reiteration of prognostic information from clinicians. The key, our bereaved parent coauthors agreed, is to raise awareness of this phenomenon and encourage clinicians to partner with patients and families living within the conceptual framework of hope and realism.

PARTNERING WITH FAMILIES

Parents of children with serious illness report loss of hope as one of their primary fears.³ Interestingly, they also mitigate this concern (ie, keep hope alive) through strategies that include restructuring hope, intentional positive thinking, cultivating a sense of control, and accepting reality.³ Although this final

TABLE 3 The Simultaneous Coexistence of Hope and Prognostic Awareness

Parent	Narrative Excerpt
1	"Hope is the antithesis of despair, not [the antithesis of] reality. The awful, painful, unavoidable reality from the moment of diagnosis, and in ever-increasing measure was that my beautiful little girl was going to die. In the midst of that sure and certain knowledge, resided hope... To be hopeful is a function of the heart and a decision of will, to be realistic is merely a function of understanding the most likely outcome. They are not mutually exclusive, nor are they at odds with one another. They do not need to be in balance, there is not a sliding scale that allows them to coexist by degrees. They are independent of one another and they are as individual as are we. Two parents, a parent and a clinician, can share the same view of reality and not share the same hope."
2	"Partner with us and witness the transformative love of hoping for the impossible and the improbable while accepting the painful reality that our rare and beautiful child is gracefully exiting this world."
3	"I feel like I was simultaneously hopeful and realistic for the entire trajectory of [my child]'s illness and death. In fact, about a week before he died, my husband, two other children, and I had a conversation around [my child]'s bedside. We still hoped that God would intervene and do a miracle in [my child]'s body. At the same time, it looked like the miracle wasn't going to happen and that [my child] was most likely dying."
4	"We continued to pray for a miracle... It was a dance. A dance between our desire and His desire, until her desire became what seemed to be evident. Then all we hoped for, for her, was heaven."
5	"We had a constant hope the whole journey that [my child] would be healed and he would live a long life. I feel like that was kind of like a big umbrella over the whole journey. But there was also more 'realistic' hopes under that big one...while maintaining all of these different hopes for [my child]'s life, we also knew his prognosis."
6	"Hope and realism were in conflict the whole duration of [my child]'s treatment. Even when the latest scans would bring good news and hope would rise, realism was like the devil on the other shoulder, always saying 'Yeah, but...' When the doctors told [my child] there were no curative options and it was time to go on hospice, realism had the upper hand by far, but hope was still there."
7	"However, until the very end of [my child]'s life, I remained hopeful that he would be one of the few patients that survives despite the odds and grim prognosis the doctors gave us."
8	"When we were told that [my child] was terminal, we understood what that meant, and we knew most likely he would die from his illness barring any other tragic event or 'a miracle'... That being said, I remember telling someone, 'We are living everyday as if it could be [my child]'s last but also as if he might live forever.' That was hope... The knowledge was '[my child] was probably going to die,' the 'hope' was he just might be the exception... In the darkest places of worry, sadness, and fear, there was the tiniest bit of light I would call hope... I knew and completely understood what we were facing, but in hope, I was not giving up on [my child]...when someone plays the lottery for a chance to win...the odds are terrible and are stacked against anyone who buys a ticket, but having a lottery ticket in hand for one day gives a person the chance to dream and wonder... Hope gives you the opportunity to dream and wonder about the possibility of your child beating the odds."
9	"The only way I could use to explain the way I felt during the time near the end of [my child]'s life is the image of the spinning dancer. Most of the time it seems so clear to me and easier to see that the dancer is spinning clockwise. Other times when I look through my peripheral vision or I am not looking so intently, my perception changes and I can see the other possibility (she is turning counterclockwise.) The reality is that there is not enough visual evidence that tells me one way or the other, but my focus tends to determine what I see...I am thinking that from a clinician's standpoint, they are often wanting parents to see the reality of which way they see the dancer spinning: perhaps counterclockwise (ie, that a child is likely to die). A parent on the other hand wants to see the more natural path of clockwise (ie, the child will continue to live) because it is so 'counter' to think otherwise of our children... It seems the ideal situation is when a clinician can use his/her communication skills not to convince a parent the dancer is spinning counterclockwise, but that that possibility exists. Somehow (through 'I wonder' statements or 'I'm worried' statements) they help the parent even for a moment to have a different focus and see a different reality while still acknowledging the existence of another viewpoint based on a lack of perfect knowledge. I knew as a parent that the possibility of [my child]'s death was a reality I had to face, but I coped by viewing the situation through the hopeful/easier viewpoint that things would work out and he would be healed...I always defaulted to my preferred reality, while still acknowledging on some level that least a few times I had seen (the spinning dancer optical illusion) spin counter to my desires, and that possibility did indeed exist."

strategy may appear counterintuitive, acceptance of reality has been shown to create space for reframing expectations ("regooling") in a way that may bolster one's capacity for hope.²⁸

Throughout the literature, parents express a desire for clinicians to recognize these tensions that they face (ie, hoping for the best while preparing for the worst) and meet them where they are during an impossibly difficult time.^{7,24} Yet continuing to endorse hope as a child approaches the end of life can create challenges for the health care team.

Clinicians may worry about enabling false hope, thereby failing to prepare the family adequately for the death of the patient. In this context, Feudtner⁷ stresses that health care professionals should not focus on judging hopes as realistic or false; instead, clinicians should strive to explore and nurture the diverse and evolving hopes of our patients and their families.

Our parent coauthors unanimously advocate for health care professionals to acknowledge and normalize the tension that exists when a parent must maintain hope while simultaneously

facing a grim prognosis. Clinicians must remember that most parents consider maintaining a positive outlook to be more important than fostering a realistic outlook.²¹ For many, being a good parent is inextricably linked with sustaining hope^{21,29}; by acknowledging that many parents perceive their role as bearers of hope,¹ health care professionals can better support families as medical circumstances change and hopes evolve.

Clinicians also can grow therapeutic alliance and support patients and



FIGURE 1

Hope and realism: hope springs eternal. Bereaved parents conceptualized a novel figure to illustrate the simultaneous coexistence of hope and prognostic understanding. This figure pays homage both to the ever-presence of hope in the face of loss and to the seasonality of the ever-revolving life cycle. The image was designed to stir feelings related to balancing hope and reality across a child's illness journey and end of life as well as to capture the profound emotions that exist in the space after a child dies. The figure who continues to hold the flower symbolizes the ever-present awareness of a parent who lives with the reality of a child's death while simultaneously continuing to live. The flower also symbolizes the legacy of the child's life, which families carry with them forever, even as they grow and nurture new generations of life. The flower embodies the past, present, and future; although it no longer lives among the other flowers, it remains through the child's lasting legacy. The petals fall both downward and upward, reflecting the power of a child's life to continue influencing those still physically living while also making an eternal impact. The flowers being watered swoop upward to the flower that is held, epitomizing the tangible connection the living continue to have with the child who died. At first glance, it is difficult to ascertain the direction of the figure's primary focus: depending on one's perspective, perhaps the figure is facing the flower, perhaps lending attention more toward the watering can, or perhaps existing within both pursuits simultaneously. A closer look at the posture suggests that the figure might be looking forward, facing an unknowable future with resolve and resilience. However, one might also imagine the figure to be looking away, focusing on the fragility and preciousness of life as the petals fall. Importantly, the caregiver also is seen watering other flowers, alluding to the daily responsibilities that exist to nurture family, friends, and work; even in the face of deep grief, the realities of duty, love, and life go on. The image was created intentionally to evoke a watercolor palette to respect how the illness and grief journey may mute some of life's deep, rich colors, yet a quiet beauty and vibrancy remains.

families by continuing to convey hope, even in the face of incurable illness.²⁹ If parents express hope for a cure or miracle, health care professionals can foster partnership by sharing in this hope (eg, "I hope for a miracle alongside you.") Such statements do not engender false hope; they simply validate and normalize the intrinsic hopes that may coexist with prognostic awareness. We encourage clinicians to consider gentle follow-up questions (eg, "And what else are you hoping for?") in an effort to prompt further conversation around additional hopes, wishes, goals, and worries.⁷ Even hopes that manifest during imminent end of life can and should be normalized for families struggling to navigate anticipatory grief. Clinicians should be cognizant that, for some patients and families, maintenance of hope may help facilitate a "good death."³⁰

RECOMMENDATIONS AND FUTURE DIRECTIONS

Bereaved parents in collaboration with interdisciplinary palliative care clinicians propose a novel conceptual model that emphasizes the simultaneous coexistence of hope and prognostic awareness. We believe that better understanding and acceptance of this updated framework may help empower clinicians in their support of families of children with serious illness, particularly in the context of approaching the end of life, while also mitigating provider assumptions that conflate hope as misinterpretation or denial.

Specifically, our parent coauthors advocate for use of this model to help clinicians (1) nurture and normalize hope as an essential aspect of coping, (2) partner with patients and families who maintain hope as they navigate the difficult anticipatory grief journey, (3) anticipate and acknowledge the tensions inherent to fulfilling a good parent role within this impossibly difficult process, and (4) mitigate

clinician distress due to fears about fostering denial or false hope. We hypothesize that clinician recognition of the coexistence of hope and realism has the potential to strengthen the therapeutic alliance and promote provision of goal-directed care. Conversely, we worry that failure to acknowledge this duality may result in undue harm to families and health care staff.

Further studies are needed to investigate whether this conceptual framework is generalizable to other pediatric centers and subspecialties. Our bereaved parent coauthors represent different parental roles and geographic regions; however, all parent coauthors are white, and we acknowledge that this as an important limitation and advocate strongly for future work to represent the diverse perspectives of bereaved parents from different races, ethnicities, and religious backgrounds. Our steering council specifically encourages additional research to ascertain whether exposure to this framework may improve parental experiences with therapeutic alliance with the health care team, decision-making, and anticipatory grief during a child's approaching end of life as well as mitigate decisional regret and complicated bereavement for parents after the death of a child. We also advocate for investigation into how exposure to this conceptual model, through didactics or experiential learning, might influence the assumptions and beliefs of health care professionals, diminish clinician distress at the bedside, and promote resiliency in the setting of emotionally challenging clinical practice.

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ABBREVIATION

HOPE: Hear Our Parent Experiences

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