Finding Hope and Healing When Cure Is Not Possible

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Abstract

Traditional medical training focused on curing disease may not prepare clinicians to provide comfort and solace to their patients facing life-limiting illness. But dying patients and their families still need healing, and clinicians can actively facilitate it. We explore the clinician’s role in the healing journey through the lens of pediatric brain cancer. Specifically, we examine how clinicians can help affected families find their way from “focused hope” (which centers on cure) to “intrinsic hope,” which offers a more realistic and resilient emotional foundation as the child’s death approaches and letting go becomes essential. Drawing on their clinical experience and medical knowledge, clinicians can help families comprehend the lessons that their seriously ill child’s body has to teach, highlighting the importance of cherishing the present and creating new memories that outlast the disease. Clinicians can avoid the mindset of “nothing more can be done,” emphasizing that there is plenty to do in providing physical, emotional, and spiritual comfort. Clinicians can learn how to be “unconditionally present” for patients and families without immersing themselves in anguish and, eventually, how to help the family find freedom from despair and a full life that still honors the child’s memory.

Physicians are traditionally trained to cure patients, to eliminate the physical manifestations of disease. However, this orientation may not serve patients facing the end of life. During such times, physicians still have a profoundly important role to play: facilitating emotional and spiritual healing. The distinction between curing and healing may seem subtle, but it is easy to appreciate when focusing on patients whose lives cannot be saved, who have diseases that simply cannot be cured.

In this article, we 4 authors—a clinician with 40 years in practice, including 25 in hospice and palliative care settings; a health services researcher who has interviewed, and grieved with, parents whose children have incurable cancer; a critical care physician who herself has endured and recovered from critical illness; and a health services researcher who has published extensively on cancer care delivery—explore the evolution of hope for patients and their families during the course of incurable illness. In parallel, we examine how clinicians can actively participate in, even guide, the healing process.

The concepts and approaches we discuss may be used in the care of a patient of any age struggling with a life-limiting condition. However, we chose to focus on children with pediatric brain tumors and their parents in part because of our familiarity with this population but also because the emotional and spiritual upheaval associated with losing a child to brain cancer is an archetypal misfortune that begs for healing. The examples we reference were gathered from personal contact or direct interviews with parents, from online testimonials of parents of children with cancer, and from publications and podcasts. Names have been altered as necessary to protect the identities of the patients and their families.

The ideas we offer are not “prescriptions for healing.” We merely aim to share what we have learned. Above all, we seek to...
augment the resilience that patients, parents, and clinicians may develop as illness advances.4

THE HEALING JOURNEY
The word heal has Old English roots, shared with words such as whole and holy. The ancient meaning of healing, associated with physical recovery from a wound or injury, also implies a deeper, more subjective transformation. Healing connotes a journey through complex, sometimes punishing, interior terrain toward a potentially more peaceful state, rich with new insights.5

Aristotle claimed that the worst disaster humans can experience, the one most likely to steal their happiness, is the death of one of their own children.6 Despite the passage of 23 centuries (and the impact of countless medical breakthroughs), parents are still tortured by the cruelest of decisions: How does the mother of a 6-year-old with cancer decide whether to put her child through grueling treatment despite a poor prognosis? How does she let go of expectations for a cure and not feel like she is failing her child? How does she navigate a pathway that might enable her and her family to cope with a child’s death?

These wrenching questions have no simple answers. Cancer and responses to its treatment are difficult to predict. Even solutions that seem definitive may turn out to be provisional because illness and, indeed, life itself evolve in unforeseen ways despite our best efforts to control them.

The foundation of healing is the evolution of hope and knowing how to facilitate patients’ passage through this journey. For patients and families struggling with life-threatening illness, hope is not an unwavering state of mind.7 Rather, it tends to evolve through phases as disease advances and death approaches. Hoping is a process that endures despite the loss of prospects for cure or recovery. According to a leading researcher on parental hope in childhood cancer, in late-stage disease, hope for cure changes into hopes that “tend to be qualitatively different from the initial hopes: they are more oriented to pain or suffering and the hope of relief, to the longing for home and the hope of homecoming, or to surviving not in a physical but in a spiritual sense and the hope of finding meaning and connection.”8

The healing process reflects the evolution of hope, a fluid framework9 not amenable to guidelines or checklists. The initial phase, “focused hope,” is familiar to all patients, parents, and clinicians dealing with serious illness.9 Focused hope centers on cure or remission. If these goals become unattainable, however, focused hope can degenerate into a kind of false hope that promotes the use of ineffective, uncomfortable treatments that may actually shorten life relative to what care aimed at comfort may offer.10 When such false hope is maintained until death occurs, surviving family members often experience posttraumatic stress and depression.11

As illness progresses despite treatment, clinicians may opt to offer honest appraisals of prognosis and treatment effectiveness. Rather than diminishing hope, clinician disclosure of prognostic information, expressed in concrete and specific numerical detail, tends to promote hope. In a subset of children in one study for whom the odds of survival were estimated to be less than 25%, parents who heard this information were 6 times more likely to report hopefulness than those who did not; those who were informed were less likely to experience emotional upset and more likely to trust their providers.12

Although some clinicians fear that full disclosure of a poor prognosis might take away patients’ hopes or cause depression,13 in fact the opposite is true.14 Parents of children with advanced cancer are able to fully comprehend the gravity of their child’s condition and still maintain hopes that help them formulate appropriate and meaningful treatment plans.15 Such patients and families benefit from clinical support that assists them to let go of focused hope. This challenging but necessary step in healing clears the way for “intrinsic hope”—a deeper, more subjective type—to emerge. Intrinsic hope replaces unrealistic expectations for
recovery with a more profound and resilient emotional foundation that, as death approaches, supports patients and parents as they prepare for the final release, the ultimate letting go.

Intrinsic hope tends to emerge in specific domains. As their expectations of cure diminish, parents report increases in hope over time regarding their child’s quality of life and the awareness of broader meaning. Quality-of-life hopes pertain to strength of family ties, finding friends, staying out of the hospital, having fun, being comfortable, and experiencing feelings such as happiness, contentedness, and peace. Hopes for broader meaning may center on God or a higher being or power, a fulfilling and rewarding life, self-identity and confidence, and learning something about life from the experience of illness.16

Hope’s evolution supports the healing journey, and clinicians can assist patients and parents through it. Several principles—all aspects of a mindset nurtured through deep reflection, not deployed like utensils in a toolkit—may help. These principles of healing apply to anyone threatened with irrevocable loss, and that includes all of us.

THE BODY IS THE TEACHER
Although symptoms of progressive illness usually provoke discomfort and dismay, skilled clinicians may sense opportunities in them. With proper support, parents may take to heart the lessons that their seriously ill child’s body teaches them, coming to understand that death is near. With that understanding, they can begin to let go of curative treatment and, with it, focused hope for remission; this release is a critical step in the healing process.17 (See the Table for the story of Sandy and her son Kenny, who had a fatal brain tumor.) This release may be difficult, however, for parents whose children have not yet suffered the symptoms associated with advanced cancer.

After much painstaking reflection, Kenny’s parents decided to stop chemotherapy, hoping his hydrocephalus might be brought under control. Although Sandy hoped something would change so that Kenny’s treatment could be resumed, this never happened. Only in retrospect did she understand that their decision had been final. Like many such parents, they prepared for an outcome they dreaded while still hoping for a miracle. Their clinicians coached them to hope for the best, but to prepare for any potential outcome.18

When children do achieve remission and get to experience symptom-free intervals at home, families can focus on being together. (See the Table for the story of Laura and her son Ben, diagnosed as having choroid plexus carcinoma that relapsed after stem cell transplant.) Parents may consciously create special moments and make good memories. That is when intrinsic hope, centered more on being in the present than on working toward future goals, may emerge. Parents hope for high-quality time together, to live fully even while planning for the end. Clinicians can play a pivotal role in giving parents time “out of the fight” to reflect and plan for an unknown future. After Ben relapsed and started an experimental protocol, for example, his clinicians altered his treatment schedule so that the family could take a vacation; they organized blood tests for Ben at a local clinical laboratory and faxed prescriptions to a local pharmacy when additional medication was needed.

Focused and intrinsic hope can merge, ebb and flow, disappear and reappear as illness progresses. Clinicians can help patients and their families navigate these vicissitudes by inquiring about their concerns, keeping an ear open for underlying feelings, and asking questions to bring them out in the open. This maneuver, a variant of the “ask-tell-ask” disclosure coaching model,19 allows the clinician to gain insight into emotional issues that could act as barriers to receiving any intended message about treatment or prognosis. These insights may enable clinicians to get on the proper emotional wavelength to get the message across, putting parents and clinicians on the same side of the table.
Sandy, mother of Kenny, a 6-year-old boy with a fatal brain tumor.
March 9, 2018: ‘Kenny has group 3 metastatic medulloblastoma with leptomeningeal spread. His cancer is no longer just in the posterior fossa of his brain. Masses of tumor and individual cancer cells have spread all over his brain and spinal column. This is what makes him terminal.’
March 17, 2018: ‘Kenny has good moments when he is engaged and happy. But mostly we’ve been trying to manage all the symptoms. Pain, discomfort, nausea, vomiting. He’s not sleeping at night, like at all. We are stopping chemo, at least until we can get his hydrocephalus under control.’
March 31, 2018: ‘It has been a very hard couple of weeks. We have had some great moments with Kenny, but also many very difficult ones. Ones that will tear your heart out. Watching Kenny suffer and being unable to give him any relief—it breaks my soul.’
April 11, 2018: ‘Three weeks ago, we were told that Kenny had days, maybe a couple of weeks at most. We were told there is nothing more that can be done for him.’
April 12, 2018: Kenny dies.
April 25, 2018: ‘The frozen moments. Living in a hospital room for 8 months. Learning the cancer is back, a relapse. A terminal relapse. Never knowing how long my son has left, but knowing the answer is not long enough. Begging God to end the suffering of my child, either by miraculous healing or taking him home to heaven. Telling my child it is okay to die. It is okay to rest, to be free of pain, of suffering. Holding my child as his last breath left his body and heart gave its last beat. Knowing I will never feel his heartbeat again.’

Laura, mother of Ben, diagnosed at age 4 years as having choroid plexus carcinoma that relapsed after stem cell transplant. Now 7 years old and undergoing experimental treatment, Ben has an unclear prognosis.
March 14, 2018: ‘When you’re in fight mode, hospitals and medical intervention become your new normal. But when you’ve had time out of the fight, away from the medical world, your perspective changes. When I see Ben with his friends, he is no longer my child with cancer. Many small things—the smell of your child, the feel of their hair on your cheek, their smile and laugh (the most beautiful sound in the world), a crisp blue sky, a gentle breeze—can make your heart sing even when it is hurting.’
April 18, 2018: ‘Doctors see a terminal diagnosis through a logical, rational lens. But to the family this is not a logical situation—it involves the most emotive decisions that anyone could ever face. This is a disconnect that must be bridged.’
May 2, 2018: ‘We have been fighting cancer for 3 years, and we are exhausted by it. The emotional strength it takes and the ability to juggle so many commitments with the needs of a child who requires a lot of medical intervention is challenging. It is omnipresent in our lives, and there is no relief. People think at some point it’s over. But cancer doesn’t go away.’
May 5, 2018: ‘I am a strong person, but I am weakened by this journey, by my emotions and my fears. After Ben relapsed, I feel like I am always expecting the worst. I don’t want to get my hopes up and then have them crushed. Actually destroyed, obliterated—I cannot find a strong enough word.’

Emily, mother of Piper, a 5-year-old girl with a terminal brain tumor unresponsive to all treatment. Emily demands further chemotherapy; when Piper dies several weeks later, her mother is shocked.
April 9, 2018: ‘Three weeks ago, as Piper was seizing uncontrollably, the oncology nurse said, “What’s her little body trying to tell you? Remember our talk about palliative care!” I said, ‘Are you serious! It’s saying, ‘Save me, Mom! Don’t let me die!’ Palliative care is not for my family. I couldn’t live with myself …. Then, when her oxygen levels were dropping, I thought, ‘Oh my God, I could lose her,’ and that feeling (pause)... no parent should have to feel that … no one, because it’s (long pause, sob) … she’s here, and she’s doing well, and I’m so grateful, and you know what, she’s going to be fine.”
April 13, 2018: ‘I’m so tired of the doctors telling me that Piper is going to die. Because I refuse to ’give up,’ they seem determined to browbeat me. I get it, but it changes nothing. I’m not going to fail Piper, no matter how many times they say it.”
June 6, 2018: Piper dies.

Even the most intense emotions may be handled using gentle but straightforward questions. One clinician, confronted by a mother irate at a recommendation to stop treatment, simply asked, “Is it possible you’re angry at me?” This question gave the mother pause, and the ensuing discussion exposed the fears that lay beneath her rage. The parents and the clinical team explored plans for the future, including preparations for death—a classic example of the shared decision making that can take place only after emotional disconnects are bridged.

LEANING ON THE DOOR
Clinicians may assist parents by helping them, with gentleness and persistence, to reframe unrealistic expectations. Clinicians who directly confront parents before trust is firmly established, however, may encounter resistance. A seriously ill body may have lessons to teach, but some parents are unable to bear them.20 (See the Table for the story of Emily and her daughter Piper, whose terminal brain tumor was unresponsive to all treatment.)

When emotional defenses seem unyielding, a determined but compassionate
approach may help. The first tentative attempt to enter another person’s inner awareness is like knocking on a door. Frightened people tend to close and lock this door, sometimes even to themselves—the essence of denial. But on hearing a knock from someone they trust, most will open the door a crack. The clinician then can place a figurative shoulder against the door, simply lean on it, and conduct a conversation through the opening without being intrusive. With enough time, the person may gain sufficient confidence and insight to open the door.

Laura explains how she and her husband came to trust their primary clinician (and team):

Our clinician responds to our questions honestly and openly admits when he does not have all the answers. He listens more than he talks. He never makes us feel rushed. He actively seeks our opinion and respects it. He is never defensive, even when we have sought second and third opinions; it is obvious to us that he wants the best for Ben. He is interested in him as a person and us as a family. Our clinician and team have held our hands every step of the way and because of this, we have been able to make very hard decisions about life, death, and late effects of treatment that we may have to live with for the rest of our lives, together as a team.

Sometimes parents’ instincts to protect their children may make their demands for treatment seem irrational. In this charged atmosphere, it is easy for clinicians to respond in ways that are not helpful, as when Emily describes the way doctors “browbeat” her with their declaration that “nothing more can be done” (Table). That statement is one that no parent, or any patient with an incurable condition, should ever hear. It not only obliterates hope but also misstates the truth. When treatment is stopped, plenty remains to be done. Hospice and palliative medicine provide intensive care aimed at physical, emotional, and spiritual comfort for patient and family, delivered both in the hospital and at home. Pediatric palliative care teams, centers, and homes are increasingly available.

Helping parents accept the need for these services, however, may require a sensitive but persistent approach. Many clinical teams have incorporated palliative care and hospice providers as integral members, easing the transition from disease-modifying treatment to comfort-focused care.

Effective communication can temper any tendency parents might have to be unduly optimistic. Clinician education and training are beneficial, but even more fundamental is self-knowledge, especially regarding intense feelings, given that those expressed by agitated parents can trigger clinicians’ own emotional responses. Emotional self-knowledge and empathy are fundamental components of healing.

When one of us (B.S.) had just started clinical practice, he feared delivering bad news to patients and parents. Reflecting on his own feelings during these encounters, he realized he was projecting his own discomfort onto the people he was trying to counsel. Over time, he practiced listening, simply being present, knowing when to remain silent and put a hand on a shoulder when words might get in the way. He came to understand that when distress was most extreme, even the gentlest recommendations to patients and parents could just add to their burden. As he became more restrained and self-aware, he developed a quiet kind of courage, which was contagious. Patients and families seemed to draw strength from it, gaining confidence in their own ability to cope and make plans.

LEARNING TO SEE IN THE DARK

Compassionate clinicians feel their patients’ pain. The literal meaning of compassion is “suffer with.” But in highly charged situations, clinicians have a choice: either block out the emotional impact for the sake of self-protection (which sensitive parents and patients may perceive as abandonment) or allow emotional connection. Total immersion in patients’ and parents’ anguish isn’t necessary or desirable. Tearing the clinician’s own heart out is not the purpose of this exercise—empathy is.
But empathy is only part of the story. Patients and parents dealing with advanced cancer often feel hopeless, lost, and alone as they try to find their way without streetlights or landmarks to an unknown destination. Laura describes herself as “being weakened by this journey … I don’t want to get my hopes up and then have them crushed. Actually destroyed, obliterated—I cannot find a strong enough word.” Clinicians who deal with patients facing death are familiar with this fear, which sometimes borders on terror.

Clinicians may not appreciate their capacity to help patients and parents through such challenging periods. Their training does not prepare them for this task because they receive little instruction in how to be unconditionally present, drawing on their ability and willingness to remain emotionally available to seriously ill patients. This may depend, in turn, on their capacity to accept any outcome their patients experience without judging it as good or bad. This might sound paradoxical, because medicine’s avowed goal is to assist patients toward recovery. However, clinging to recovery may lead clinicians to regard death as failure, emotionally abandoning terminal patients.

Unconditional presence keeps clinicians connected with patients even during the worst of times, “worst” being in the eye of the beholder. Parents wrestling with the shock, fear, and disappointment of their child’s terminal diagnosis gain reassurance from clinicians who can hear and accept those feelings while staying centered in their own confidence that whatever happens, steps will be taken to confront setbacks, relieve symptoms, and allay anxiety.

This attitude may equip any clinician to help patients and parents confront fear, uncertainty, and loss by acknowledging the nature of darkness and helping them navigate it. This could be conceived as a form of spiritual care distinct from religion, although many clinicians skilled at providing it may not conceive it as such. However, patients who receive such support from their medical teams undergo less aggressive care at the end of life, fewer intensive care unit admissions, and higher rates of hospice use than those who get spiritual support from their own religious communities.

With practice, clinicians can learn to accompany others through the darkest places, demonstrating deep emotional empathy while staying centered. For example, one dying patient requested that her favorite pediatric anesthesiologist perform a final intubation in the middle of the night. The physician left the lights off, arranging to have Mozart’s flute concerto playing as she sedated the patient and performed the procedure, the parents sitting at the bedside. The physician later reflected, “This was my most extraordinary intubation. It was a sacred moment in my life. We are so privileged to walk beside our patients.”

THE OTHER SIDE OF DESPAIR

Despair is an agonizing consequence of incurable disease. But recognizing and handling it properly, resisting any temptation to avoid it, may represent a critical stage in the healing process. One mother, in her book telling the story of her son’s dying from a brain tumor, says, “Despair caused by unrealistic expectations is so much worse in my experience than facing the bottom line—death—and being realistic about what you can achieve before that happens.”

Despair after the death of a loved one differs from major depressive and posttraumatic stress disorders. This despair constitutes an acute grief reaction, which may respond well to supportive care and informal counseling. Nevertheless, parents who exhibit prolonged shock and disbelief, anger and bitterness, or suicidality may be experiencing complicated grief, a condition to which bereaved parents are particularly susceptible, and which may benefit from specialized intervention.

Despair can’t be “fixed,” it must be lived through. This is a serious challenge for families already under extreme, prolonged stress that has overdrawn their emotional bank account and worn their resilience down to a nub. Just when life-or-death decisions need
to be made, the energy may run out. At these times, “I'm not willing” may degenerate into “I'm not able.”

In this setting, it may be helpful to conceive of despair not as a monolithic impasse but as a multilayered problem that might be disentangled and resolved over time, bearing in mind that the loss of a child, or any loved one, leaves a hole in survivors’ hearts that may never be filled. But that void is often shrouded by layers of physical distress (exhaustion, financial challenges, neglected family responsibilities) and emotional concerns. Approaching and resolving these challenges one by one can strengthen parents’ ability to cope. But sometimes the best clinicians can do is to keep faith for parents who may, for a time, be incapable of keeping it for themselves.

The clinical tasks are to formulate concrete goals of care that include plans for the end of life (an act that significantly relieved parents’ psychological distress) and to convey, through companionship and gentle guidance, what most people who have lost a loved one eventually learn: life awaits on the other side of despair. For instance, one of us (B.S.), who counseled the parents of an infant boy who died of an intractable cancer, was told several months later by bereavement counselors that although the parents would never stop grieving their son and the impact of their ordeal, they had gone on to have another child and their life was full and happy.

Some grieving parents find solace in talking with others who have lost a child to illness. For instance, George Mark Children’s Place in San Leandro, California, the first pediatric palliative care home in the United States, has more than 150 volunteers, many of them experienced parents providing support through home visits, workshops, online support groups, and phone calls. Bereaved Parents of the USA, a not-for-profit, volunteer-only organization with chapters across the country, publishes newsletters, maintains lending libraries, and holds monthly support meetings as well as its Annual Gathering Conference.

HOPE FOR FREEDOM

Freedom is the end product of hope’s evolution. Sandy says she arrived at the point of desiring to let go because she wanted her son Kenny “to be at peace” (Table). In this way, death may be a release from suffering for patients, parents, families, and even clinicians.

Parents (and clinicians) may wrestle with guilt as they yearn for release from the yoke of illness and its treatment. Laura comments that being a good parent is often seen as fighting for the life of your child and never giving up. But she also observes a sharp distinction between giving up and making a conscious choice to let go. Clinicians can support patients’ and parents’ yearning for, as a national leukemia researcher puts it, “the peace, the comfort, the joy and the sense of completion when a person chooses to live unencumbered by the demands of modern medical therapy.”

Families often yearn for their own freedom from the ordeal of cancer itself, as Laura reflects:

Our lives are hijacked by this disease. People give up their jobs, leave their children to be raised by others, live in the hospital where they barely have time to shower, think, sleep, or eat. No one wants to lose their child, but being free from the constant stress, worry, and anxiety of this journey would be an enormous relief.

The ultimate manifestation of hope may be spiritual freedom. What parents value, and what clinicians can help provide, is a sense of purpose and peace of mind. Sandy puts it this way:

Especially in the end, there is hope. Sooner than our hearts desire, Kenny will be free. He will walk again. He will dance again. He will laugh again. Free of pain. Free of suffering. Free of the limitations of his world.

For religious people, spiritual freedom may be embodied in an afterlife. For others, simply imagining their child unleashed from
the burdens of cancer may bring freedom. Any of us, touched by this eternal present, might feel a moment of peace; just a glimpse can last a long time. Many clinicians have found their own freedom by facilitating this process of healing for others. Discouragement, feelings of failure, even the despair of burnout, may be healed by accompanying patients and parents on this journey.

CONCLUSION
As patients and their families affected by incurable disease navigate the complex journey of healing, and as the nature of their hopes evolves in profound ways, clinicians can play a crucial role. This involves knowing when to give gentle guidance, when to speak and when not to say a word, when to intervene (and to what degree), and when to get out of the way. In the best of circumstances, the healing power of a clinician’s presence may complement, although it can never match, the devotion of parents to their dying child. Nevertheless, clinicians can learn to sense opportunities in reports of patients’ symptoms, help them reframe those perceptions with gentleness and persistence, develop the courage to accompany people through dark passages, and recognize freedom as an ultimate goal. All of these discoveries help foster healing. They can empower patients, parents—and clinicians—to find life on the other side of despair.

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