Holding on to Hope

Parental beliefs & emotions in Pediatric Palliative Care
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Stories, photos and case studies in this presentation will not reveal the names or identifying information of any actual patients or family members.

I have no actual or potential conflict of interest in relation to this program/presentation.
The Paradigm Shift of a Child’s Serious Illness
Parents of children with advanced, life-threatening illness may face excruciating decisions about their child’s medical care.

Thinking about a child’s mortality is something most parents – and many healthcare professionals – do not feel prepared to do.

The unexpected illness or premature death of a baby, child or teen does not fit our expectations of “how things are supposed to be.”
Regardless of one’s faith or spiritual practice, a health crisis is often a spiritual crisis.

Illness disrupts one’s life and routine, and distorts what a person believes to be true about him/herself, and about the world.

When facing a crisis, one’s primary spiritual needs may come to the surface including: connection, community, meaning, love, peace and HOPE.
“Illness is both soul-shaking and soul-evoking for the patient and for all others for whom the patient matters. We lose innocence, we know vulnerability, we are no longer who we were before this event, and we will never be the same.”

J.S. Bolen, MD

Close to the Bone: Life Threatening Illness and the Search for Meaning
Holding on to Hope becomes a primary goal.
So what is HOPE?

- An expectation and desire for a certain thing to happen
- A person or thing that may help or save someone
- Grounds for believing that something good may happen
- Confident expectation that things will be well
- The certainty that God will provide
- A feeling of trust
- Faith
HOPE

is the little voice you hear whisper “MAYBE” when it seems the rest of the world is shouting “NO.”

– Unknown
What does Hope look like?
Hope may look like:

- Focus on a Cure
- Return to Normalcy
- Optimism
- Wanting/wishing something to be true
- Denial
- Belief that all will be well
- Faith in the Future
- Not giving up
- Trust in God’s Providence
- Confidence in the medical team
- Waiting for a Miracle
Why is hope so important?

- Hope shapes perspective and guides decision making
- Hope impacts one’s ability to cope and adjust
- Hope can provide stability and resilience to go on
- Hope impacts recovery and/or the grieving process
- Hope helps make meaning out of struggle
- Hope can sustain parents in the dark days surrounding the illness — and even the death — of their child.
Hope can promote Healing

- Belief and expectation – *key elements of hope* – can block pain by releasing endorphins and enkephalins.
- Hope can also have important effects on physiological processes like respiration and motor control.
- During the course of illness, belief and expectation have an impact on the nervous system, which sets off a chain reaction that makes improvement and recovery more likely.

— Jerome Groopman, MD

*The Anatomy of Hope*
Hope may buffer us from stress, anxiety and the effects of negative life events.

– Shane Lopez, PhD

*Making Hope Happen*
Humans look for Hope

“The natural flights of the human mind are not from pleasure to pleasure, but from hope to hope.”

–Dr. Samuel Johnson
Dashed hopes can lead to despair

“If you lose hope, somehow you lose the vitality that keeps life moving, you lose the courage to be; that quality that helps you go on in spite of it all.”

– Martin Luther King Jr.
When discussing medical treatment options for life-threatening pediatric conditions, parents’ specific hopes regarding their children and the care that their children receive are fundamental motifs, combining both thoughts and feelings about the current clinical situation and possible outcomes.

— Feudetner, Carrol, et al
Unrealistic Hopes

It doesn’t ultimately help parents and patients if we support and encourage false hopes, or let the hopes of the healthcare team drive a treatment plan of futile care.

We are not “taking away their hopes” if we tell them the truth and help them transition their hopes.

Not telling them the truth *may* take away their choices for meaningful time at end-of-life.
The line between hope & denial

<table>
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<tr>
<th>False Hope</th>
<th>True Hope</th>
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<td>- Does not recognize the risks and dangers that true hope does.</td>
<td>- Displays a commitment to the truth and reality.</td>
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<td>- Is more about positive thinking than reality.</td>
<td>- Takes into account the real threats that exist.</td>
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<td>- Can lead to intemperate choices and flawed decision making.</td>
<td>- Seeks to navigate the best path around them.</td>
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– Jerome Groopman, MD
Parents of children receiving palliative care have reported faith as the basis of decision-making, making sense of their situation, guidance in daily existence and end-of-life discussions, and as a way of coping with their current circumstances.

— Meyer, Ritholz, Burns & Truog
A parent’s beliefs may define their hopes:

- The expectation that God may heal their child
- Their understanding that there is value in suffering
- Their belief in an afterlife
- Their belief that God will be with them, no matter what happens.
Learning from our Pediatric Patients

Harbingers of Hope
The ability to cope with illness and loss is affected by one’s mindset. Children have a natural resilience in crisis because their minds are not yet “set.” While parents struggle to maintain established beliefs, the malleable hearts and minds of their children adapt creatively to crisis, incorporating new experiences into their “pictures” of life. We can learn from the stories and artwork of children, who find hope, because they look for it.
Learning from Children

*Mindset vs. Malleability*

- Adults often have mindsets (set minds), plans and expectations.
- Children are often more malleable; pliable; flexible.
- They reshape their hopes and expectations to accommodate new experiences.
- Children often have the ability to maintain hope and navigate life’s transitions, challenges and disappointments because they are able to incorporate new experiences and ideas into their pictures of life.
People are pathways to Hope

- Literature tends to treat hope as only an existential experience, virtue or emotion.
- But studies with chronically ill children reveal that hope is a social resource. It emerges through interactions with the people who surround us. (Duane Bidwell, PhD)
- It is important for the patient’s “team members” — family, doctors, nurses and chaplains — to do things to help create and activate hope pathways for the patient.
Stories from the Pediatric ICU
Resilient Children

The Girl with the Purple Hair

The Karaoke Boy
Helping Parents Cope

In the face of their child’s illness
Having hopes for their children is one of the things parents do best. They start practicing even before birth.

- What will my child be like?
- Will he be a baseball player like his dad? A writer like her mom?
- I want the best for my child.
- It is my job to be my child’s provider and protector.
- I want my child to have the things and opportunities I never had as a child.
- My child is special, and destined to do great things.
When a child has a life-limiting illness, parent’s goals and strategies for their child’s life may need to be drastically altered, especially if possible early death looms. Families may access sources of faith, hope and spirituality to make this transition.

— Cheryl Crisp, PHD, PCNS-BC, CRRN
When a child becomes ill

- When a child is hospitalized with an illness, or born with complications, the parents and family begin the journey with hope, even in the midst of their fear and shock.
- They *hope* that the test results will be negative; They *hope* the child will spontaneously, even miraculously, recover. They *hope* that life can continue as normal.
When the diagnosis is confirmed

When parents know the truth about their child’s condition, they may begin to place their hope in other things:

• That the medical team “knows what to do.”
• That the stage of the illness won’t be too severe.
• That the child will avoid dangerous or difficult treatments or procedures such as chemotherapy, extended hospitalization or surgery.
• That life will get back to “normal” as soon as possible.
Sometimes parents are forced to redefine “normal” and revise their hopes for the future.

- When it is clear that extended hospitalization, radiation, chemotherapy or surgery will be a part of their child’s life, the focus of their hope shifts a bit.
- Parents may still hope for a successful outcome, but they begin to consider the possibility that things will not end well (from a medical perspective.)
- They may vacillate between realistic hopes, fear and denial.
“We are still hoping . . .”

- That we can get through this
- That our child will adjust well
- That our child won’t be in too much discomfort, pain or distress
- That it won’t be too hard on our other kids
- That our marriage will survive the stress of our child’s illness and hospitalization (and death?)
When there is “no hope” of a cure

- Sadly, for some families, the outcome of the child’s illness will be death.
- When the medical team communicates that there is “no longer any hope” (medically) the parents and family may be emotionally and spiritually devastated if they have no other hope to hold on to.
- Children and families are often resilient however.
- They begin to look for hope in different things
- They may hope for as much time as possible with their child before death; or an opportunity to say or do things they really want said or done.
Parents of dying children may hope for . . .

- Meaningful time with the child before death
- Being with the child at death
- That their child will not suffer or be afraid
- The ability to move on and continue living, to be there for other children, spouse
- Hope of transcendence; Hope in an afterlife
- That the parent-child relationship continues forever “In our hearts & memories”
- Hope that their child’s life had meaning, and “made a difference” in the world
Holding on to Hope

Holding on to hope can be a source of great comfort and strength to the patient and family as well as the medical team.

Parents have echoed the importance of hope as a way to survive emotionally, as well as to try to find meaning in what that they are experiencing.
One parent of a child who died stated:

“Hope is essential; don’t give it up. Even now, I realize it was so important.”
Hopes vs. HOPE

- Hopes for their child and hope are not necessarily the same.
- Verna Hendricks-Ferguson PhD found that hope was a “comforting and life-sustaining, reality-based belief that a positive future exists.”
- That hope or future may be a heavenly one, as opposed to an earthly one.
- But a future remains. And that future may sustain them through their present crisis.
When asked, parents may describe their belief in an afterlife, discuss heaven as a happy place, and state that everything happens for a reason, whether they like it or not.

– Hexem, Mollen, Carroll, Lanctot & Feudtner
Regardless of gender, culture, race or religious tradition, over 90% of the parents refer to seeing their child again in Heaven.

Our annual Pediatric and NICU Remembrance events bear this out.

To My Mummy and Daddy

God took me early,
He didn’t want to part,
He thought me extra special,
But I know it broke your heart.

I give you hugs and kisses,
whenever you want to cry,
And when we meet again someday
I’ll forever be by your side.
Studies Reveal:

the importance of parental affect and patterns of hopeful thinking in the process of decision making when confronting serous illness. They strongly suggest the need for clinicians to be aware and respond to these influences.
Partners in Hope

As members of the healthcare team, practicing patient and family-centered care, we can be part of the “Pathway to Hope” for parents and families.

We can assist parents and decision makers by:

- exploring the range and variety of their hopes in a non-judgmental manner
- examining the thoughts they have about these hopes
- further informing or supporting these thoughts and hopes.

– Feudtner, et al.
“My son was diagnosed with a brain tumor. At first we hoped there would be no cancer. But when there was cancer, we hoped it would be in the early stages; that he wouldn’t need chemo. When he did need chemo, we hoped it would be effective; that our child would survive. Now we are hoping our marriage and family will survive if we lose him.”
The Last Crane

– On parenting a dying child –

By Jacqueline Dooley
The best we can hope for may be transforming hope.

Hope that transitions over time.
Hope that finds meaning and sustains love and faith.
Hope that offers a possible “YES” when life says “NO.”
Discussion of Case Studies

- As you read your case, identify some of the hopes of the parents and family.

- What might be the hopes of the medical team?

- How might the parents’ hopes transition over time?

- How might the support and/or hopes of the medical team become motivators? Obstacles?