

Until the Last Breath

Exploring the Concept of Hope for Parents and Health Care Professionals During a Child's Serious Illness

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Objective: To investigate the concept of hope for families and pediatric health care professionals during a child's serious illness.

Design: Eight focus groups.

Setting: Academic pediatric medical center.

Participants: Bereaved parents, pediatricians, pediatric residents, and nurses (N=39).

Intervention: Participants were asked standardized questions related to their definition of hope, its role in medical decisions, and the benefits and detriments of hope in focus group sessions.

Main Outcome Measures: We identified attributes of participants' concepts of hope using qualitative analysis of audio-taped sessions.

Results: While all participants identified common elements in their definition of hope, parents identified their role as bearers of hope; it was a cornerstone of decision making. Health care professionals tended to view hope as related to a positive outcome. Some physicians reported difficulty in maintaining hope in the face of prognostic data; others acknowledged the importance of the family's hope. Nurses identified particular challenges around parents' decisions to continue treatment when it prolonged the child's suffering. All participants noted the changing nature of hope and its implications for care.

Conclusions: The tension between maintaining hope and accepting the reality of the prognosis may lessen when acknowledging that parents see their role as bearers of hope. Supporting families around the changing nature of hope may allow health care professionals to partner with parents while maintaining honest communication.

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OBSERVATIONS FROM CLINICAL practice reveal a situation that often arises during a child's serious illness: a family's desire to maintain hope in the face of a poor prognosis. Bereaved parents express maintaining hope as an important factor in how they coped with their child's illness. Some health care professionals are concerned that a family's expression of hope may be related to their inability to accept the reality of the situation or that they may be unable to convey honest or direct communication about the poor prognosis expressed by the health care team. One implication of this tension is that health care professionals worry that a family's focus on hope may lead to continued aggressive treatment that may cause the patient needless suffering.

A review of the literature indicates that the concept of hope is being explored in greater depth in recent years in medical, nursing, psychology, and pastoral care journals.¹⁻⁷ Many studies explore the medical value of hope related to cancer survival rates

or lack of hope and increased mortality, with contradictory results.⁸⁻¹⁰ One recent study explored hopeful thinking and the level of comfort in providing pediatric palliative care among hospital nurses.² However, no studies have directly addressed how families and health care professionals interrelate about the concept of hope and its impact on coping and medical decisions.

The objective of this study was to investigate the concept of hope and its effect on coping and medical decision making from the perspective of bereaved parents and pediatric health care professionals during a child's serious illness.

METHODS

Focus groups were held with bereaved parents, pediatric attending physicians, residents, and nurses at the Johns Hopkins Children's Center in Baltimore, Maryland, from September 2005 through June 2006. Based on a review of the literature and clinical encounters, the guiding principles for the study were to learn how parents and pediatric health care professionals define hope, assess the role hope plays in medical de-

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DEFINING HOPE

Table 1. Questions for Focus Group Sessions**Question**

How do you define hope?
 What role did hope play in making decisions for your child/providing care for your patient?
 How important is hope in coping with your child's/patient's illness?
 How did hope change over the course of the illness?

cisions, and explore the benefits and detriments of hope related to care during a child's serious illness. Standardized questions were developed from these guiding principles (**Table 1**). We (a bereavement coordinator [E.A.K.R.] and a physician [J.R.S.]) conducted the focus groups. The bereavement coordinator is skilled in group facilitation; the physician was present to hear responses and to ask for clarification.

To maximize responses and determine if different ideas arose with different participants, 2 focus group sessions were held for each participant group (bereaved parents, attending physicians, pediatric residents, and nurses) for a total of 8 focus groups. Bereaved parents were recruited by an opt-in letter by inviting every third name in a hospital database of those bereaved for at least 1 year. Fifty-four letters were mailed; parents were eligible for participation only if they affirmatively responded to be contacted for the study. Health care professionals, which included attending physicians, pediatric residents, and nurses, were recruited by e-mail announcements and fliers. As health care professionals who guide and implement the medical care, physicians and nurses were selected as participants since they were the health care professionals who expressed tension or conflict around the issue of hope. A total of 39 people participated in the focus groups: 12 bereaved parents, 10 attending physicians, 8 pediatric residents, and 9 pediatric nurses. Of the 12 parents, 9 mothers and 3 fathers participated and their children's age at time of death ranged from 2 months to 21 years. Attending physicians (5 female, 5 male) included representatives from pediatric intensive care (n=4), general pediatrics (n=2), and oncology, hematology, neonatal intensive care, and pediatric emergency medicine (n=1 from each). Pediatric residents (7 female, 1 male) included 2 postgraduate year 1, 3 postgraduate year 2, and 3 postgraduate year 3 residents. Nurses (8 female, 1 male) were from pediatric oncology (n=5), neonatal intensive care (n=3), and pediatric intensive care (n=1). The duration of the focus groups ranged from 60 to 90 minutes. The study was approved by the institutional review board at Johns Hopkins Hospital and written consent was obtained from each participant. A light meal and a \$5 gift certificate to a bookstore were provided.

Each session was audio taped. Transcription was performed by one of us (E.A.K.R.) and a review of the tape was done to verify accuracy of the transcription. All participants were offered the opportunity to speak with one of us if they had additional viewpoints that they wanted to share outside of the group dynamic. The bereaved parents were contacted by the bereavement coordinator 2 weeks after the study to assess if any emotional or spiritual issues surfaced after participation. Two parents and 1 nurse expressed additional opinions; none of the parents expressed any emotional or spiritual difficulty from participating in the study. One parent reported that it was helpful for her to hear other parents' perspectives. The other parent and the nurse offered additional reflections on their comments. Qualitative analysis was used by us in reviewing the transcripts; themes were identified in response to the questions. Any discrepancies were resolved by consensus by us.

All participants consistently identified the following common themes in defining the concept of hope: association with positive outcome, future oriented, coping strategy, relation to spirituality, and a concept innate to human nature. Examples of their statements are found in **Table 2**.

THE ROLE OF HOPE IN DECISION MAKING

The 2 themes that emerged in response to this question were balancing hope with accepting the reality of the prognosis and without prolonging the patient's suffering.

Theme 1: Balancing Hope With Accepting the Reality of the Prognosis

Parents explicitly addressed this theme in their comments. One mother stated,

Hope was the cornerstone in all of our medical decisions. Hope was the source of being able to rise above your physical and mental limitation under all that amount of stress. . . . You could do it because you were hoping if you just took good care of him and you did everything you were supposed to in making the right decisions, he'd do all right.

Some parents described the necessity of having hope as part of their role as a parent:

There is hope here even though it's pretty dire. And that definitely affected the decisions we made. . . . My job was to have that hope and be a positive influence.

Our role [as a parent] is different. Our role is to protect our child and do every last thing for our child. . . . having lost our child, you have the long burden of grief. . . . parents live with these decisions so you have to make sure you do everything possible.

Parents also tended not to view this theme in tension (ie, an "either/or" situation) but were able to maintain these elements as coexisting variables. One father stated,

It wasn't really a point of giving up hope but acceptance of the outcome.

On the other hand, health care professionals did note tension in trying to balance hope with accepting the reality of the prognosis. One attending physician stated,

It's a challenge to the health care team if there is a discrepancy in hope which sees the prognostic sense, and as long as it doesn't interfere with the way in which the health care team is able to go about its work. . . .

Another attending physician acknowledged,

I think it's hard to maintain hope, trying to pay attention to what you know.

Nurses worried that parents were hopeful because they had not been given honest information. Two nurses stated,

A lot of times I think when they have hope that's unrealistic they just don't have a true understanding of what's going on.

As long as they are very aware that what they hope for might not happen but still they want to focus on their hope, I think it's a wonderful thing. I have a harder time when they either refuse or have not been explained the real picture of what's going on.

Table 2. Quotes From Participants About the Elements of Hope

Element of Hope	Quote From Participant
Association with positive outcome Future oriented	"To me, hope is the expectation of something good." (nurse) "Hope always implies potential and so in having hope, it's, it is optimism but it's also implying that there's a future, that there's something to be had beyond this moment in time." (pediatric resident) "Hope is me thinking about what I want to be true of the future. That's kind of what I think about hope, maybe not what I expect is going to be true or what I predict or prognosticate is going to be true but what I would like." (attending physician)
Defense mechanism	"I also see hope as somewhat of a defense mechanism. I think it's an innate attempt to deal with diversity, to deal with things that are difficult to deal with and it allows you to trudge forward. I think for some families, it's a good psychological defense mechanism." (attending physician)
Related to spirituality	"For me, I believe that you have to have some type of spirituality first to get through any situation in life, but as far as being hopeful, it's like, okay this is bad, but we want to be able to make a good day, just live each day." (parent) "I define hope as acceptance that no matter what happens, it's going to be okay and this kind of spells out everything." (parent)
Innate to human nature	"I think hope from a family standpoint is driven by love that we can't even conceptualize personally in that situation as health care providers. I think it's the love for that child that drives that hope. I think that's maybe an element of the parent-child bond." (nurse)

Theme 2: Balancing Hope Without Prolonging the Patient's Suffering

This second theme of balancing hope without prolonging the patient's suffering was not a universal theme for parents, but many spoke about it poignantly. One mother stated,

I didn't want to keep it longer than I needed to. . . . I think it's hard to differentiate your hope as a parent and the real hope for the child.

Two other mothers described this tension specifically in terms of selfishness:

You hope that he gets better and you pray that they do the next step and then you realize that a lot of that is you selfishly wanting him to be here or wanting your child to make it no matter what. . . . So it's not giving up hope, it's getting to that place where you know you're praying for them to be there selfishly and their life wouldn't be right just to stay here for you.

At one point it was selfish that I love you so much that I'd do anything to keep you here . . . but at what point is enough . . . enough?

This theme was shared by all health care professionals. One attending physician stated:

The situations where I'm as sure as I can be of anything that a child's absolutely not going to survive . . . and I think the child is suffering and yet the family insists that continuing treatment is the best thing to do.

Other health care professionals were concerned that the result of continued treatment could lead to suffering for the patient. One pediatric resident stated,

My conflict, as well as the team, was a feeling that we were prolonging the suffering of the child by doing more interventions.

Nurses were more apt to discuss how they have handled providing care in the face of this tension:

The child to me was obviously suffering and needed to pass but the parents weren't together. The father wasn't ready at that point and mom was. I think just trying to set aside my feelings that this isn't my child.

If the family . . . still has that hope, that's where we need to let them go with that and this is their child. . . . if they never get ready and then the child dies, well then that's what the family needed to do. I think I'm becoming more respectful and aware of the very particular situations that each family finds themselves in.

THE ROLE OF HOPE IN COPING WITH THE ILLNESS

Health care professionals acknowledged the value of hope as a coping mechanism. Both bereaved parents and health care professionals recognized that hope is a survival tool in coping with serious illness.

Nurses noted hope's value as a coping mechanism even if the medical team disagrees with parents' decisions:

Their child has gone through such suffering this year and it has been very hard to watch and their hope hasn't accepted any refocusing. It's like a bold . . . armor of coping mechanism. It's been hard for all of us on the team to be able to . . . accept that this is how they're coping, that we have to respect it and travel with them.

I actually hear a lot of our parents say, "I just have to hope" and I think they know that there really is not good reason to hope but they decide to do that anyway because that's the way they're going to survive.

One resident stated,

If I could put myself in the position of the family . . . I can see that I would adhere much more to hope than I do as a practitioner.

Parents also noted how hope helped them to cope with their child's illness:

I just lived. We just lived for each moment and everything and it's okay. You just finally say it's okay even when it's not okay . . . you just have to find someone, as sad as it may sound, worse off than you.

THE CHANGING NATURE OF HOPE

All participant groups noted ways that hope changes over the course of illness beyond an expectational hope for a physical cure for the child to a desirability hope.¹¹ These desirability hopes might be related to hoping the child lives long enough to accomplish a goal or see a specific person. As one attending physician noted:

Hope for some of those families meant something very different. . . . if they could hope that the baby would live long enough that the grandparents could see it, or that the mother could hold it, that was enough and so sometimes I think we think of it in big-picture terms but for the families even a small part of hope is enough.

Table 3. Quotes From Participants About the Changing Nature of Hope

Quote

- "I feel like I've done my job well in facilitating the kind of change of hope, to help a family come to acceptance . . . sort of new understanding and new hope." (nurse)
- "If there's just nothing more you can do and death is imminent, just help them focus their energies on being with their child, doing everything that they can for their child while he's still here." (nurse)
- "It comes down to helping them understand what their hope is . . . that their hope can be for their child to die and help making it be the best experience that it can be." (nurse)
- "I think we can try to channel hope into different corridors." (pediatric resident)
- "Every patient should have some level of hope, hope for the final days, so I think physicians have a role for hope in terms of guiding the parents to the appropriate level of hope." (pediatric resident)

The shift in hope could also be related to factors after the patient's death as evidenced in these statements from a parent and a nurse, respectively:

Hope changed from earthly hope to a heavenly hope when my daughter says she was going to heaven and at that time she would have new legs and she would dance.

Hope lasts until even after a child dies, . . . but then parents tend to hope that all their friends come to the funeral, hope they're remembered in certain ways so I don't think hope is ever gone.

The overall theme that emerged from this question about the changing nature of hope was that physicians and nurses see it as their role to facilitate a shift in the focus of hope (**Table 3**).

COMMENT

To our knowledge, this is the first study to investigate the concept of hope from the perspective of bereaved parents, physicians, and nurses during a child's serious illness. The role of hope is complex. Even though all participants identified the same common elements in their definitions of hope, parents and health care professionals approach hope differently in the context of a child's serious illness. While all participants were questioned about the same dynamics of hope, parents and health care professionals diverged on how they emphasized and endorsed different aspects of hope. Health care professionals described a tension between the emotional aspect of hope and intellectual understanding of the prognosis. They seem to approach hope related to a child's serious illness from the association with a positive outcome, such as a physical cure. Physicians desired that parents should acknowledge the possibility of a negative outcome if they were still going to hope and nurses feared that parents had not received accurate information about the prognosis, concluding that if parents had done so, they would have made a choice to stop treatment. However, parents spoke about their role as bearers of hope and protectors of their children, which could indicate they are operating from the concept of hope as an innate aspect of humanness and parenthood. Many of the parents seemed able to acknowledge the emotional component of hope

while still understanding the intellectual prognosis and did not see these states in competition with each other.

The culture of health care seems to have led to the idea of the "medical" value of hope as a means to prolong life. Schneiderman feels an

essential task for physicians in the modern era is to discard the conventional, narrow view of hope as a means to prolong life.^{12(p238)}

Indeed, while health care professionals tended to view the balance of hope with accepting the reality of the illness in tension and conversely related to the prognosis, parents from this study tended to view these elements as coexisting variables and as part of their role as parents for the duration of their child's life.

It seems crucial then that health care professionals understand both their own framework for hope, as well as how each individual family approaches hope. In ethics literature, explanatory frameworks suggest hope stems from people's worldview of beliefs, values, and behaviors.¹ A disparity between the explanatory frameworks of parents and health care professionals can lead to tension in the relationship, illustrated by some of the comments from health care professionals in our focus groups.¹ In addition, even the language we use for treatment may compound the relational tensions, as medical treatment is now often referred to as medical care. Therefore, suggestions to stop treatment may be perceived by parents as suggestions to stop caring for the child.¹³

While there are some validated scales about assessing hopefulness, they were developed to address individual hope in a terminally ill adult patient, not parents of a terminally ill child.^{7,14,15} The viewpoint may differ since a patient can make his or her own decisions while a parent must make decisions for their child by proxy, suggesting a different level of decision making. Clinical care and communication may benefit by the development of a scale to measure hopefulness in parents and the explanatory framework that underpins their beliefs and decisions in order to foster a therapeutic relationship between parents and health care professionals.

Another way to account for the different emphases of the dynamics of hope that emerged for parents and health care professionals can be found in the nursing literature from the Mishel theory of uncertainty. The premise is that an uncertain prognosis can be viewed as a threat or an opportunity.¹⁶ Health care professionals tend to view uncertain prognoses as a threat (and therefore want parents to acknowledge the possible negative outcome), while parents view the uncertain prognoses as an opportunity or possibility for a good outcome (therefore holding on to hope for their child). Since it is very difficult to prognose serious illness in children, some propose that in the face of uncertainty "hope is always warranted."¹⁷

The other aspect that arose from how hope affects medical decisions was the balance between maintaining hope without prolonging the patient's suffering. Some parents viewed hope as selfish if it led to their child experiencing continued painful interventions and the health care professionals identified the potential for prolonged suffering as a challenge for their practice.

So how can parents and health care professionals communicate most effectively around the concept of hope? Par-

ticipants in these focus groups identified the changing nature of hope as one bridge. In shifting from “expectational” to “desirable” hopes,⁷ the focus moved beyond physical cure to manageable goals. Indeed, the strategy of goal-directed interventions around hope has been studied with adult patients¹⁸ and redefining hope is a suggested intervention for nurses to support families¹⁹ and for physicians, as an effective communication strategy.²⁰ Another strategy is to communicate with parents about hoping for the best, yet preparing for the worst. This allows for balance between the parents’ hopes for their child and the health care professionals’ desire that families understand the probable realistic outcome.²¹ Included in this strategy would be to confirm that the parents understand what was communicated by the health care professionals. Part of the tension, especially for nurses, is wondering whether the conversations have happened and that the parents have understood the information shared. Communication strategies could be used, such as asking parents to repeat back what was described or to share their understanding of the situation. Thus, if parents could repeat back what the physician told them, it would ensure they did indeed receive accurate information. The next crucial step would be to communicate this conversation with the interdisciplinary team so that all members would be aware of the conversation and decisions made.

The sample size was small and the focus groups were limited to 1 institution so results may not be generalizable. Participation in the focus groups was voluntary so opinions of those who chose not to participate could reveal very different themes. While the facilitation of the focus groups allowed everyone to speak, it is possible that a group setting may have deterred some participants from expressing their views or their thoughts may have been modified by the opinions of others. However, all members were given opportunities to share additional opinions and viewpoints. Future focus groups might benefit from having members of the different participant groups present within the group, as well as expanding the health care professionals who participate to include other interdisciplinary team members, such as social workers, chaplains, and child life specialists.

The concept of hope is a complex factor in caring for children with serious illness. Understanding that parents do not see a tension between maintaining hope and accepting a poor prognosis may alleviate concerns for health care professionals. Helping health care providers to understand that families may be able to maintain both their emotional necessity to have hope and understand the intellectual concept of the prognosis may help alleviate the tension. Supporting families around the changing nature of hope may be a bridge for health care professionals to partner with parents while maintaining honest and accurate information. Our data serve as a background on which future research can build. This could include surveying participants to determine which concepts of hope are operational within their role as health care professional or parent, exploring ways to assess and communicate a family’s explanatory framework about hope to the health care team, and developing educational interventions for health care professionals to minimize the tensions that can exist. Examination of this complex topic may lead to better healing, communication, and support within the health care partnership.

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