

**Communicating What Matters By Pamela S. Hinds**  
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I hope you are all doing well and I thank you for inviting me to talk with you about a child's end of life. It's an amazing time and I'm hoping today to tell you about a strategy that I believe if you and I could build it into our care systems, we could protect the well-being of parents and the families who will lose a child and I'm calling that strategy *The Invitation*. And for those of us who are healthcare clinicians who wants so much to be certain of everything at a child's end of life, it's also an *invitation* ourselves to be surprised.

We struggle with a child's end of life to actually define it, describe it, and most certainly to predict it. So we know it's ambiguous but we also know it's a period of life where [00:01:00] the meaning of being alive begins to decrease and on that period of living ends with death. So we would in pediatrics that a child's end of life is both biology and human values. As health care clinicians, we do have some confidence about the biology. We know what to do to help a child who's suffering and the family, biologically. But we don't know about this unique child's human values, or the human values on those who speak on behalf of the child. We cannot know unless we ask and that's the *Invitation*. So the child's end of life, that period of living, is really a period of invitation.

In general, in life, when you and I think about an invitation, we think about words, perhaps verbally written offered to [00:02:00] us to do something with someone, go somewhere with others, who we think we have something in common with, and we actually hope there'll be a good outcome from the invitation. But without a doubt, that invitation is from a person to others. It's an invitation for a human connection. But at a child's end of life, that *invitation* is that and more. It's really trying to find out what it is that is of much importance to this child now. And to this family. Now. And if we ask, listen, or told to act on that in a way that could ease the future for this family. The future that will be long without the life of this child. So it's an invitation that comes at a time [00:03:00] when we want so much to look as if as clinicians that we know what we are doing and yet an invitation means we must be willing to surprise, to ask, to listen, and then to act on words while we still have time — while the child still lives.

Most children in America die in a hospital. That means that those of us who are clinicians have every opportunity to do something with our actions, our words, to make it better for the family that will survive the loss of this child. And to do it in a way that is effective, low cost, low burden, and will travel with the family as they leave our care and step into that future [00:04:00].

So for the last 25 years or so, I've had the great privilege of working with children who are not going to survive a fatal illness. And during that time we have worked together to talk about their hopes and to talk about what role they had in making their end-of-life decision. When talking about their hopes, they're very clear with me. That they know the difference between a hope and a wish. And hope is something like wanting better for those who will also be diagnosed in the future. Wanting their partners not to be too sad too long versus a wish. We tend that they have something to do with some nice object. Knowing that the hope was reality-base and the wish, very unlikely.

And when talking about end of life, the number one factor that influenced [00:05:00] them in making their end-of-life decision was caring about others. But always at the end of our time in the study they would say to me, "Please would you do this very same study with my parents? I'm worried about them." Why would a child who's at end of life worry about a parent? Why

would you and I worry about parents who are losing a child to death or have already lost a child to death? And that's because there's a subgroup of parents who suffer extraordinarily. They die younger, they have to leave the workforce because of health, and may have a first psychiatric hospitalization. They are the vulnerable amongst us. We must be able to do something for them while they are within our arms [00:06:00] and so far in America, the majority of children, between 60 and 70 percent, still die in the hospital. So I did accept the invitation from these children who would not survive and I did begin working with their parents. And when I listened to them, asking the question, what was it that they had thought about when they were making an end-of-life decision for their child, they were able to identify for me nine different factors. I think many of these you would intuit. And as a study team, we did as well. Things like no more treatment, wanting the end of my child's life to be good... or doing as my child would prefer that I do.

But across studies, there was this one factor that we honestly didn't know the full meaning. And what parents kept saying was, "I want to do [00:07:00] as a good parent would do for a seriously ill child. I want to decide as a good parent would decide for a dying child." And we knew that if we were to understand this human value, we had to do another study and really invite parents to teach us about this human value. So we approached this, having even learned how to ask the question. And the question asking the invitation to be in a relationship with us as a healthcare team went something like this: "Parents, whose child is very very ill, have taught me that they have an internal definition of what it means to be a good parent to a seriously ill child. Please would you share with me your definition of being a good parent to your very ill child now?"

We've now been [00:08:00] been able to ask that question to over 400 parents and importantly, all of them had an answer. No one hesitated to say "I don't know what you're asking. I don't know what you mean." They all understood what it means to be a good parent when your child's life is under threat. And they're able to give us key categories of answers about what it means to be a good parent to a seriously ill child. Most certainly, every definition is unique, and therefore merits the invitation to be in a relationship with the team by asking the good-parent question. But there are commonalities.

And I'd like to share a few of them with you:

- Being able to make unselfish and informed decisions on behalf of my child.
- Being able to advocate for my child with a staff [00:09:00] even if it means that these people I trust will get mad at me.
- Remaining at my child's bedside no matter how difficult.
- Helping my child to know that he or she will not be alone when they die.
- And most importantly, helping my child to be certain that I as a parent, have loved him or her well.

In what we know from our research, is that even first-time parents who give birth to a child who is fatally ill already have an internal definition of what it means to be a good parent to this very ill infant and if we but ask, give the invitation for this human connection, their answer will help us and guide us in giving care to this very ill infant and the family [00:10:00].

Further, parents are very sure about what it is that we do with healthcare clinicians to help them achieve their definition of being a good parent to their very ill child. And I'll share with you just a few of those — and please, if you would, look for what is the commonality amongst these:

- Staff respecting me and my decision.
- Staff comforting me and my child.

- Staff knowing our unique needs.
- Staff asking us about our faith and respecting it.
- Staff not quitting on us.
- Staff telling us that we are good parents, and...
- Staff not forgetting us when we leave here with or without our child.

What is so common **[00:11:00]** across all of those parent identified strategies for how we can help them to achieve their definition before the child dies, is our relationship. It's a human connection between us as clinicians and they as the parents. And it's a human connection that we can step into at a child's end of life.

So if we believe that a child's end of life is both biology and human values, and that we cannot know the unique human values until we ask the good-parent question, then we should be building our healthcare systems to include that question. If we ask, we listen and we honour those words, we have every chance to help protect the health of parents and thereby the well-being of families. I thank you very much.

[Crowd Applauding]

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