

[MUSIC PLAYING]

SPEAKER:

I want to ask a couple of questions first. How many of you here finished your residency in the last seven years in the teens? How about in the naughts, between 2000 - 2009?

In the '90s? In the '80s? In the '70s? Anybody from the '60s? I remember the '60s. Yes. Good times in the '60s. And you've taken care of a lot of patients that I know, too. Glad you're here.

The other thing I want to ask before we start, is how many of you, in your primary care practices, see at least one kid every week who has a chronic, complex condition that they're going to have for the rest of their lives? Almost everybody.

And if you practiced-- if you've finished your residency like I did, before the late '90s, it's unlikely that in your training that you had experience with palliative care programs. So I'm going to, in this 30 minute slot, just share with you five patient stories that kind of paint the picture of what's worth worrying about in this field of caring for our sickest, most vulnerable kids. Some of whom you're going to be seeing in your practices, but who are going to be spending a lot of time in the hospital and with specialists.

I have no financial conflicts. I want to identify some of the both practical and ethical challenges and talk a little bit about support services that are currently here and things that we need to grow and to have better. Because we are failing these children and their families in lots of important ways.

When we started a palliative care program in 2005, the business plan said that we would see 48 children every year for the first few years. And in the first year we saw 125. And last year we saw over 700 kids were consulted to the palliative care team. About half on the inpatient service and half on the outpatient service.

What was surprising to me, as I got sucked into this by good nurses and started doing this, is that two things surprised me.

Number one, most of the kids that we were asked for did not have cancer. Which was my preexisting idea, that palliative care was for kids that were going to die of cancer.

And it turns out-- not only in our institution, but in the other children's hospitals that have had palliative care teams and oncology teams-- only about 20% of the things that we get asked are to help support kids with cancer. Most of them are helping with kids with other chronic congenital diseases. We had about 20% of our business comes from the congenital heart center, kids with complicated, often single ventricle diseases.

The other thing that's surprising is that I thought that when I got sucked into palliative care that I'd really be spending most of my time figuring out how to deal with distressing symptoms of pain, shortness of breath, sleep disorder, etc. And that turns out to be less than a quarter of what we get asked to do.

Mostly what we get asked to do is to help with decision support. And that's what we're going to talk about is cases that involve high quality decision support. And figuring out how to best make good decisions for kids. That if you are like half of us in the room, who finished training before the mid-'90s, a lot of these kids were not surviving back when we were in training. But now they are.

So we're going to talk about the new tools. These four interventions, of tools that were done, were all there when I was a resident. Although some of them became much more prominent, even in the '80s when Cheryl back here and I were in our training.

I think that Broviacs just came in when we were residents back in the early '80s. We were so glad that we didn't have to do the blood draws and the IVs ourselves once they got these things.

What's surprising about looking at this picture, for those of you who care for kids that have g-tubes, trachs, Broviacs, and shunts, there's something that's out of my experience, and with other people's experience, when you look at this picture.

And we ask, what is different from your experience when you look at this picture of these kids with these technology helps? They're all smiling.

Now kids with these things smile. But when we encounter them as doctors, they're not smiling. They're usually sick when they have these things. And some of these kids actually have all four of these things.

Well those things have been around for a long time. But I'm going to talk about a patient each who's had one of these other interventions meant to help them, invented to help them get through a crisis, and be well again.

But the fact that we now have these three extra technologies, we're left with kids who are either non-survivors or who survive with even more morbidities than they came in with.

And what our challenge is in our children's hospital, in our group practices, and in our palliative care teams, is to figure out when these tools need to be used. And this ends up being about half of what we do in the hospital on the palliative care team is meet families and meet care teams that are dealing with kids that are up against problems that initiate these therapies.

I'm going to tell you a story about each one. I met Ben and his mother about four years ago. And his name really wasn't Ben. And this wasn't really his picture. But Ben had trisomy 18.

And back when I was a trainee, and even 15 years after, children with trisomy 18 were often supported. But the expectation was that they would have very short survival. But starting back in the '90s, children with trisomy 18 have been, often appropriately, treated more aggressively with surgical interventions and things to keep them going longer.

But Ben's mother brought him to our palliative care clinic after having had the first 11 years of his life in another state. And recalled the story of when Ben was an infant, and he developed bronchiolitis.

He was intubated in the emergency department, taken to the ICU, and when attempts to extubate him failed, she remembers being told, if we don't do a trach and put him on a vent, your son is going to suffocate and die a terrible death.

Jump ahead to when we met her. And she said, his life has been terrible. He doesn't have any interaction. He doesn't smile. He's had many admissions to the hospital. And what's my alternative? Well, after lots of talking-- with Ben's mom, with other doctors that were involved, with the family-- it was decided that we would focus the rest of his life on keeping him comfortable.

He was eligible for hospice. And the next time he got a respiratory infection, care was not increased. But care to maintain his comfort was maximized. And Ben died a peaceful death at home. And mom said, if I had known there'd been an alternative, I would have never agreed to the tracheostomy in the first place.

Our hospital has a large, chronic, stable vent program with over 200 kids right now, in the state of Michigan, that are followed by that program that are home with tracheostomies and at-home ventilators. Now many of those kids are going to do well.

There are kids that were preemies, that had premature lung disease, bronchomalacia. They required vent support, maybe for a year or two, and got the trachs out when they were three, four, or five.

A friend of my son's just graduated from Michigan State having been one of those kids. And he's got a good job out in California now. And he was a success of the chronic vent program.

Other success stories are for the second indication for chronic vents, which were kids that had spinal cord injuries. Like Christopher Reeve had a trach and was on a vent. And those things can be very supportive for people who agree that this is the way that I would like to live.

However, a lot of kids that start out on this program don't make it long. I don't have updated slides from the last nine years. But a large number of these kids, about 20% of them, will die in the next 10 years. And most of them die from their underlying disease and not from complications of the vent or the trach.

The second case I'm going to tell you about is the use of another tool that wasn't around 20 years ago, and that's continuous renal replacement therapy or continuous dialysis. They use this as hemodialysis that goes on 24/7, again, to get people through a crisis. And it has great advantages for these kids who are going to recover.

Let me tell you the story of Micah. This is my Micah's picture. And Micah's mom is a huge advocate for palliative care and the support that we were able to give Micah, his healthy twin brother, and his family.

Micah was a 27-week preemie. Unlike his twin, developed most of the complications of prematurity. Although he never had an intracranial hemorrhage, he had necrotizing enterocolitis, developed cholestasis from TPN, and, most significantly, an acute kidney injury. That after months of waiting for his kidneys to open up and to start peeing again, it never happened.

This was a tough decision for our team. He was the smallest baby. He still weighed less than 1,600 grams when continuous renal replacement therapy was started.

But it kept on. And after four months, he was transitioned to intermittent hemodialysis. His initial hospital stay was almost nine months long. And he went home on six day per week, coming back to the hospital for hemodialysis.

He was smiling and interactive when he wasn't sick. He had great family support. They lived 15 minutes away. But four weeks after he went home, he came back septic-- respiratory infection-- spent four weeks in the ICU, and then died before he was a year old.

This is another tool that when it works, great. But a lot of times it doesn't. And when kids die who have been in the ICU on this therapy, most of them--

Out of 270, just over 10% were previously healthy and had an infection or an injury or something that came up that caused their kidneys to fail. Most of them, again, the ones that died-- and this is the number that died. This is not the death, this is the survival on the right hand side of this-- that half the kids that had gotten CRT alone were dead at six months. And if you were both on CRT and ECMO-- which is our next case-- you only had a likelihood of still being alive after six months of 24%.

So let's go to case three, was our ECMO patient. Now ECMO is the heart-lung bypass machine that works for respiratory failure and cardiac failure. And it can really get people through a crisis.

In fact, the survival from ECMO in pediatrics is better than in adults. Because what the ECMO team is always hoping for is another previously healthy child, adolescent, or young adult who just has terrible influenza, terrible pneumonia, and they need to bypass their lungs. And they get better.

The other group that our cardiologists like are kids with fixable cardiac disease who, with a little bit of ECMO to help them get through, will get better. Or kids with congenital diaphragmatic hernias, who the surgeons fix, and they can get them on ECMO.

However, ECMO is now-- because the machines are out there. And unlike organ transplant, we're not limited and don't have to put people in a hierarchy of worthiness to get it. If you have heart or lung failure, it's going to come up as a conversation.

And some people think that in 10 years, there'll be a home ECMO device that you can take at your home. And just make sure that your primary care pediatricians have a space for the ECMO equipment to wheel in a special room. It might be important.

Case three is Hazel. This is not her name or her picture, either. But this is the case of a little girl with trisomy 21 and a tracheoesophageal fistula, who-- despite a very early in her life repair of her tracheoesophageal fistula-- had a persistent leak and persistent stenosis of her esophagus. By age 17 months she had been to the operating room 23 times for surgical attempts to get her better.

The best month of her life was when she was 17 months old. She had not been in the OR for four weeks and was happy and interactive. And then golly, golly she got RSV and pertussis at the same time and ended up in respiratory failure on maximal ventilatory settings, had pulmonary hypertension developed.

And the pediatric surgeons who knew her from all of these visits to the operating room. I had a great relationship with her. She was so cute. And when they asked the parents, what do you want us to do? They said, we want you to do everything. Save our baby.

They cannulated her in her neck for ECMO. And she was down for 10 minutes without a heart rate or perfusing pressure and got CPR for 10 minutes. When they lightened up her sedation and her paralysis, she wasn't moving her left arm and leg. And her head CT showed that she had a stroke. Heavy sedation.

Fast forward another two weeks, not showing signs of improving coming off the vent. The nurses were distressed. The fistula was still leaking.

And it wasn't until day 30, when all attempts at both communication-- talking to Boston, talking to Cincinnati, saying, is there another center that might be able to help this child-- she was withdrawn from ECMO support and died within 10 minutes.

And the parents expressed great thanks at all the efforts. And the biggest thing that the palliative care team was doing during that time was helping to support not only the family, but the surgeons and the nurses, and making sure that she was comfortable enough with all the heavy sedating medicines, that the child herself was not was not suffering.

So like our CRT slide, that survival having received any ECMO at all-- and this is from combined data from all the centers around the United States that do ECMO-- almost half the kids have died within 30 days.

I know that our representatives in Washington are discussing, and maybe voting today, on the Repeal and Replace the Affordable Care Act. And the word affordable is always an interesting one that goes into any of these discussions.

This one ECMO admission. This is Hazel. Anybody want to guess what the total charges were-- hospital professionals-- for a week on ECMO. Knowing the charges don't mean this is what insurance is paying. It's usually somewhere around 44%.

But the charges will just tell you what it is if you don't have insurance, what your bill will be. Anybody want to guess? It's a lot. \$1.2 million for a month on ECMO. \$1.2 million in charges. So we expect to collect a little below \$600,000.

The trach vent kid-- this is not Ben, because he was in another state-- but we've had another child with trisomy 18 on a vent who is still alive. But in two years had 18 admissions, many of them in the ICU. And his charges were \$3.8 million for these multiple admissions.

And the last was our CRT patient. And this was Micah, who had the two admits in his first 10 months of life. And that one was \$4.3 million. This is expensive, expensive care.

This slide just says that in our pediatric ICUs around the country, the black lines are kids with chronic, complex disease-- those kids that I asked you about-- that are never going to be better. They spent a lot of resources in the ICU.

And these are all the different parts of ICU care and expense. And the gray bars, going from the right to the left, are the percentage of all those expenses and interventions that are in the chronic, complex care kids.

So even though we've got these new tools, our challenge, as health care providers and as palliative care specialists, is to help parents figure out, and the teams to figure out, when is it right to start, not stop, or not even offer. When is it time to stop?

My second two cases don't involve children that are in the hospital when we're talking about the challenge and what we need to do better. Because this is the other half of what we do as a palliative care team, those 350 kids that we see in the outpatient.

I'm going to just tell you about a patient each on two continents. The second one was one that I met when I was on my four month sabbatical in England.

Well this is Paul-- real picture, real kid from Jackson Michigan-- who had cerebral palsy seizures, scoliosis, all the common complications of kids that are wheelchair bound, that are in the special schools with lots of support. Happy, happy kid who wasn't sick very often, but was on a lot of meds and he saw lots of specialists.

When he was 14 years old he started to get sicker. His seizures got worse. His urinary tract infections-- which had been intermittent-- now we're not only more frequent, but multidrug-resistant.

And like many kids with bad cerebral palsy, they develop feeding intolerance. And they're g-tube feeds just stop working. They start vomiting and getting distended.

He'd had three admissions and six ED visits in a 10-week period. And in March a year ago, mom asked, is it time to think about hospice for him? She'd known some other families in the same school that had benefited from hospice care.

And what mom had recalled was that when-- if Paul's pediatrician from Jackson is here, I don't want to say anything bad about you-- but mom said, that every time I called the pediatrician when Paul was sick, she'd say, this is above my pay grade. This is not what I was trained to do, to take care of a kid with this many problems. You better take him to the ER.

Because he'd had urinary problems, she called the urology clinic. Well, his surgeon was in the OR all day. And when somebody finally called her back, they said, you know what? We don't know. Call the infectious disease specialist. This is what happens to kids with chronic, complex problems.

And when I ask any of these specialists, could he die from this? They look at me like I'm crazy. No, we fix kids with these problems all the time.

But he eventually-- when all of us got together who were involved in his care, realizing what mom was saying, was that Paul is through fighting. He doesn't want to be back in the hospital. He doesn't want to go home with a PICC line. So he died about 10 weeks after he entered hospice, very comfortable, surrounded by his family at home.

I just want to contrast that with some home support that are available for kids in Great Britain that aren't yet available here. But we're working on it. The guy in the wheelchair is a little 16-year-old, a big 16-year-old, named Derek who had Duchenne's muscular dystrophy.

As a benefit of the National Health Service, he has a home health nurse-- and he has since he was an infant-- who comes and visits him every month-- and who is available on the phone-- who helps the family talk about advanced care plans and what's the next thing to do and knows the specialists that he's involved with.

In addition-- not part of the National Health Service, but part of philanthropic efforts in all parts of the UK-- they have a respite home called Douglas House for adolescents and young adults where they get 16 days per year-- and they usually take this in three or four days chunks-- where they can come to this house. Their family doesn't have to take care of them. The team at the Douglas House takes care of them.

When they're 18, they go at 7 o'clock in the evening after dinner. They roll down in their wheelchairs to the local pub and have a good time. And they also have a sexuality policy for these young men that I can give you more details of later.

So there's some things there that are really important that we are trying to figure out, can we do this in Michigan? There are some things that they do better. And there's a few things that we do better for kids with life-limiting conditions.

We have well-developed hospital programs, which they don't. And when our kids are in home hospice, we have nurses that will go out and visit them at 2 o'clock in the morning. And they don't. They can bring kids to these hospice residences for end of life care. But we do better in a few other places.

So what's the future of out of hospital support? Our program, together with Hospice of Michigan, is putting together a proposal to the Michigan Health Endowment Fund to get a grant to pilot a program like they have in England. Not with the building and the respite and the pubs and the sex policy, but with programs that can have a nurse that's available to help these kids at home who are likely to live for years and not for months.

They're not eligible for hospice. Because you have to have a likelihood of survival of less than six months. And you have to have a family that's willing to accept that. There is a lot of these kids that families aren't ready to accept that death is coming around the corner, but could really benefit from better services.

So we're starting this in conjunction with right now my hospital and the Hospice of Michigan. And we hope within a couple of years to bring into DeVos Children's Hospital of Michigan, Beaumont, and our other children's hospitals.

We know that in order to get this to work, we're going to need to need carve outs from payers for these chronic, complex kids. It's been demonstrated in other programs, particularly in California, that if you enroll children with these chronic, complex conditions into a program with a home nurse and availability 24/7 to call somebody when your kid is sick, it saves up to \$3,000 per patient per month to the payers. And we can invest some of that back in services that can help keep them better.

What's the future of the Affordable Care Act, Obamacare? How is this going to impact it? I don't know. I think children are going to be relatively politically more safe than those of us who are dealing with the same issues that our elderly parents or-- maybe for those of us who finished our training before 1985-- for ourselves.

The last thing I wanted to share with you is that the other thing that's going on that you may be able to help with is to go to the website. And this is going to be on the loop.

The Children's Palliative Care Coalition was formed just a year ago this month. And this was a group that came together of everybody in the state was invited. And we've got about 130 members now-- both individuals, pediatricians, specialists, bereavement specialists, hospice workers, palliative care workers-- that are members of this organization that is meant to discuss and come up with group solutions to many of these problems.

If you join the group, you'll be invited to participate in one or more of our work groups in this organization which are working on these aspects of care for kids with life limiting conditions that will help. We share our experiences, our expertise, our priorities. And ultimately we'll be using our combined efforts to effect changes in payment, changes in state law, and the practice of better medicine for these kids, who back in 1985 were not surviving but now they are.

And it's our responsibility not just to patch them up, but to keep their families as functional as they can be, these children as happy as they can be, and importantly, accepting the fact that their lives are going to be short, but they don't have to be awful. Thank you very much.