Biography
Dr. Betty Ferrell, PhD, RN, has invested over 40 years practicing and researching hospice and palliative care practices for pediatric and adult care. Dr. Ferrell currently serves as the Director and Professor of Nursing Research and Education at City of Hope National Medical Center, where she has worked for more than 30 years. She is the Principal Investigator of the End of Life Nursing Education Consortium (ELNEC) project. Dr. Ferrell has authored and co-authored over 440 journal articles and numerous books, chapters, and monographs. Dr. Ferrell has been awarded for her work throughout her career, and most was inducted as a member of the National Academy of Medicine in 2019.

Interview Abstract
Dr. Ferrell begins with her personal introduction to the need for palliative care and hospice from her experience working as a nurse in adult oncology. She describes how she stood alone in her quest to delivery better quality end of life care and decided to pursue her PhD in order to supply the data needed for this emerging field. After years of research and practice Dr. Ferrell joined forces with other hospice and palliative care leaders to expand the field or research and practice to pediatric medicine. She explains how she was drawn to pediatric palliative care and the need for specialization within the field of research. She explains the advancements that have taken part in pediatric palliative care over the past ten years as the specialization has gained greater attention. Dr. Ferrell then goes on to describe some of the changes and challenges presented to pediatric palliative care, citing health policy to be one of the greatest barriers. Finally, Dr. Ferrell describes her greatest successes and her aspiration for all clinicians receive training on palliative care before entering into practice.
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>DRD</td>
<td>Dividends Received Deduction</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>ELNEC</td>
<td>End of Life Nursing Education Consortium</td>
</tr>
</tbody>
</table>
### Interview Roadmap

#### Beginnings

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal career influences</td>
<td>4, 6-8</td>
</tr>
<tr>
<td>Educational background</td>
<td>5-6</td>
</tr>
<tr>
<td>Mentors and other influential figures</td>
<td>8-9</td>
</tr>
</tbody>
</table>

#### Connections between adult and pediatric hospice and palliative care

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction of pediatric palliative care to adult curriculum</td>
<td>9-11</td>
</tr>
<tr>
<td>Influence of adult hospice movement on pediatrics</td>
<td>11-12</td>
</tr>
<tr>
<td>Barriers to the pediatric field</td>
<td>12</td>
</tr>
</tbody>
</table>

#### Pediatric end of life care

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specializing in pediatrics</td>
<td>12</td>
</tr>
<tr>
<td>Developments in palliative care</td>
<td>13-14</td>
</tr>
<tr>
<td>Challenges</td>
<td>13-15</td>
</tr>
<tr>
<td>Strengths and successes</td>
<td>15-16</td>
</tr>
<tr>
<td>The Future</td>
<td>16-17</td>
</tr>
</tbody>
</table>
### Related Works and Mentions

<table>
<thead>
<tr>
<th>Mention</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kubler Ross, Elizabeth</td>
<td>4, 6</td>
</tr>
<tr>
<td><em>And the Band Played On</em></td>
<td>5</td>
</tr>
<tr>
<td>Foley, Kathy</td>
<td>5</td>
</tr>
<tr>
<td>Coyle, Nessa</td>
<td>6</td>
</tr>
<tr>
<td>Wolfe, Joan</td>
<td>11</td>
</tr>
<tr>
<td>Hymes, Pam</td>
<td>11</td>
</tr>
<tr>
<td>Lotstein, Debra</td>
<td>12</td>
</tr>
<tr>
<td>Lafond, Deb</td>
<td>12</td>
</tr>
<tr>
<td>Batista, Vanessa</td>
<td>13</td>
</tr>
<tr>
<td>Hafkamp, Amy</td>
<td>13</td>
</tr>
<tr>
<td>Saxton, Cheryl</td>
<td>13</td>
</tr>
<tr>
<td>Walker, Gay</td>
<td>13</td>
</tr>
</tbody>
</table>
Today is August 22, 2019. I am Bryan Sisk and I am in St. Louis, Missouri interviewing Dr. Betty Ferrell over the telephone for the pediatric palliative care oral history project. Dr. Ferrell is in Duarte, California. Thank you, Dr. Ferrell, for joining me. To get us started, can you just tell me when your mind turned toward palliative care as a career focus?

Betty Ferrell: I think, honestly, I've been in palliative care before there was palliative care. So, I began my career as a nurse 42 years ago. So, the year end of 1977, I graduated from my bachelor's degree in nursing. And my first position was as a staff nurse in oncology, which was also a new area, the first oncology unit in my hospital. But from the beginning, my interest in oncology was really around what we would now call palliative care. So, patients at the end of life, symptom management, pain control. And then it was two years later that I began to hear about hospice. And then, of course, many years later when I began to hear about palliative care.

Bryan Sisk: Was there any particular moment or experience that really turned you onto this focus on end of life? Or was it just in general begin in oncology and being drawn to that?

Betty Ferrell: I remember one of the first. It was not the first day but it was definitely within the first few weeks of working on oncology which was adult oncology. I was an evening shift nurse and I was answering the call bell from one of my patients. I walked into the room and it was an older gentleman with prostate cancer with widespread bone metastases. And the man was just in, just excruciating pain, just immobilizing pain. And this was, of course, at a time where we did very little. We had very little. We did very little to relieve pain. And I walked into this dark room in the evening shift and here was this very frail -- a man who was so miserable. He really could hardly speak to me. It was sort of a whisper of saying, "Can you help me?" And it was sort of the defining moment for me of like, "Well, this is exactly why I became a nurse," was to try to help people like this gentleman in terms of pain and comfort. And just acknowledging that this man was going to die because this, of course, was also at a time where no one spoke of death. And certainly, I mean there was no hospice in my state. There was -- I don't think we -- well, I'm sure we didn't even know that word yet. It was the beginnings in the UK but there was no such thing in the United States as a hospice. So, I just immediately knew this is why I want to be a nurse, to provide comfort and to deal with people who are at the end of life. So, that
was sort of it. And from there, I made career choices and decisions to focus my career in that direction.

One thing that's interesting is how quickly you moved through your education. I've interviewed a number of other really instrumental figures who have a nursing background and, for a lot of them, they worked for several years as a nurse and then they took some time and then they did their master's and they took a couple more years and then they started their PhD. But it looks like from when you finished your nursing degree to when you finished your PhD was only seven years. So, what was your big drive to go through that education?

That's an interesting question because when I finished nursing school, I really didn't enjoy school much. I was working full-time while I was going to nursing school. And, so, it was sort of an insane time of life and all I wanted to do was graduate. Just get me out of my bachelor's and I promised I wouldn't go to school again. Like never, ever, ever.

And, so, I finished my bachelor's and I started working and I was very happy in what I was doing. I had no academic interest but working as an inpatient nurse. What really happened was I began to encounter some patient situations that I wanted to change. So, for example, this was at a time where we still had placebos for pain management. A patient would be in pain, you'd call the physician. The physician would say, "Well, you know, I don't know if he's really in pain. Why don't you give him a placebo? Give him a saline injection. If he's still hurting, call me back." So, that was the status of care. And, so, that was one of the things that I just thought, "This is horrible." And there were a couple of other things so, I -- it was really moral conflict. I mean I didn't know those words at the time but I just thought, "Wow. There's got to be a better way."

And, so, that was my impetus. I thought, "Well, you know, I have a little voice. I mean, I have no power. I can't change anything." And, so, that was -- I thought, "Okay. I'm going to go back to school." And my intent was to go back and get a master's degree because the idea of advanced practice nursing was new and I wanted to get a master's degree. And, at the time, there was no such thing as a nurse practitioner. They were -- if you got a master's degree, you worked as a clinical specialist. So, that was my goal was, "I'm going to go back to school, even though I never wanted to go back to school. Still don't really want to go back to school. But I'm going to go back to school and get a master's
degree because that will give -- will put me in a position where I can write policies and have a voice and change practice."

So, it was very -- my interest in going back to school was very much, "How can I change practice?" And once again, I went back to school. I thought, "Okay. This is -- this will be the end point. I don't really want to do this but I'll go do this so that I can go back to the bedside and do what -- do clinical practice."

And then, I did that. I got my master's and I really enjoyed that. I began to see the bigger picture. The fact that you really could use your advanced knowledge or your advanced role to impact care. And then it was my last semester of my master's degree that I sort of had an “a-ha” moment that what I really needed was data. This alone was probably not going to make a difference. And that what I really needed was research skills. I needed data to change things. And, so, I -- then fairly quickly, after finishing my master's, I said, "Well, I got to do it. I got to get my doctorate." And, so, I made a pretty quick, finishing the master's and starting the doctorate. And it was -- but it was all about I need -- I need data. I now have the voice and I'm arguing with people about why placebos aren't a good idea. But then everybody's saying, "Show me the data." So, I thought, "Okay. I'll learn how to do research so then I'll have data." So, that was my return. So, I did sort of plow through my educational degrees a little earlier on than others did. I'm grateful that I did that because I have been able to use the PhD and my research skills throughout my career, for now a long career. So, and, kind of get it over with. Right?

Yes. Absolutely. So, when you were starting out and you were working at the bedside and noticing these things that you wanted to change. Were there others of similar mind on this? Or did you feel like you were kind of alone in your thoughts?

I was really quite alone for many, many years. I spent the first 30 years of my life in Oklahoma. So, I went to school in Oklahoma and Texas. Got my PhD in Texas. And there were no hospice programs. The word palliative care didn't yet exist. And there were really -- there was really no one else who had this interest in hospice or palliative care. And then about -- I mean about the time I was finishing my PhD, then there was -- that was the very beginnings of like the first -- I was a part of the first hospice starting in the state of Oklahoma. And, so, that -- it was -- there were beginning to be at least a few people interested in the idea.
I think that was largely influenced by -- when I started my career, for many years, “healthcare” meant the hospital. There was nothing else. It was all the hospital. So, if a patient was sick, if they had pain, if the family was exhausted, it was just, "We'll come to the hospital." So, there was no such thing, really, as home care. There was no such thing as hospice at home.

And, so, what happened was when the DRGs came to be and, so, suddenly reimbursement changed and we had this strong mandate then to get people out of the hospital. That was really, "Let's do the development of hospice, of -- we got to -- this idea. We don't want people dying in the hospital and we want to get them out of the hospital." So, that was how hospice came to be. And that was really the beginnings of kind of a group of people becoming interested in hospice care.

And then in 1987, I moved to California and taught for two years in a university. But then realized that I really did want to focus my career in my research. And, so, I came to City of Hope. So, this is my 30th year I've been at City of Hope. And this is really -- this 30 years has been my opportunity to develop my program of research and the ELNEC project and everything that I've really been focused on now for most of the last 30 years on palliative care.

So, walk me through the experience with it. Was what it like to be -- to have these thoughts, to have this drive that put you into the master's program and then the PhD program. But then to be kind of alone without having a lot of confidants. What was that like?

It was interesting because this, of course, is far before there was anything called the internet. It was before there was a web. And, so, how you even communicated or how you found knowledge was a very different world. And, so, you couldn't Google it. Right? So, I remember probably about 1980 in some by chance bookstore finding this paperback book by Elizabeth Kubler Ross on death and dying1. And it was just like a world opened to sit and read this book. Sort of in my living room in Oklahoma, I'm sitting here and reading the book. And it was -- these pages. Like these are the words. This physician writing about the conspiracy of silence around dying. This physician writing about how there are better ways to help people who are dying and to be a sacred experience that -- it was -- that was sort of my connection.

---

There weren't people around to have these conversations with or organizations or a newsletters or the web or anything else. I think the first professional meeting I ever attended was about 1983. And because of the growing interest that I had, I went to the National Hospice Meeting. And again, that was just life altering to go to this conference that was with people from around the country, all basic, very grass roots, starting hospices in their state. But the whole program where the topics were, pain management and bereavement support and very, very early on.

So, I mean I remember when the first hospice in America started in Connecticut, this first program. And it was -- maybe you read a little blurb about it in Time magazine or something. And it could've been in Mars, it was so removed. And then sprinkling: Oh, there's a second hospice starting in California. Oh, did you hear there's a third hospice starting in New York? So, it was still so young and like I said, the word palliative care didn't exist in our vocabulary. And certainly, it was a very -- it was sort of slow.

But then it was this progress. It was fast-moving then over the next 10 years and there were many hospice programs. And then I remember clearly -- I remember going to one of those early -- maybe it was that first national hospice meeting. And in the bookstore or the book exhibit at the hospice meeting, I had heard about this thing called AIDS. I mean very -- just vague. One sentence somebody said about this disease called AIDS. And I picked up a copy of the book And the Band Played On\(^2\). And I read the book on the plane on the way home. I think I then drove to my house and kept reading. I think I stayed up all night. I mean I think I literally read that big book cover to cover. And it was just mind-boggling, this idea that this disease that was called AIDS and that -- and that these young men were dying and that there was no care for them.

So, again, that was a huge thing for me. But it's fascinating to look back now and say that's how slow knowledge was advancing because you had to read about it in a published book. Right? And that there was no network, there was no community to foster this commitment to the field. And of course, the world has changed so much in a relatively small period of time.

\(^{[00:16:12]}\)

**Bryan Sisk:** Did you have any mentors early on that were guiding you through

---

Interviewer: Bryan Sisk
Interviewee: Betty Ferrell
August 22, 2019
Page 11 of 18

this? Even if they weren't specifically interested in what became palliative care?

Betty Ferrell: No, my first -- I really had no mentors in my community or my work environment at all. My first mentorship really happened in like the early '80s. The first few meetings that I attended -- or maybe it was more like mid -- now that I think about it, more like late '80s. And it was really before there was palliative care, before I was very well-connected with hospice.

It was the world of pain management, because there was this pain community developing with all these new products to treat pain, and morphine availability, and American Pain Society was this organization. So, I remember going to my first few meetings about pain, and that was sort of the precursor to palliative care.

So, for example, Kathy Foley, was the physician at Memorial Sloan-Kettering who started the pain program. But I look back now and all of these pain programs developing around the country. They were pain programs but they were really doing palliative care, because there certainly wasn't anybody else doing palliative care. You might get a consult. Can you come see this patient for pain? But this patient was dying. So, you were -- even though it was the American Pain Society or it was the pain conference, it was the place where you could talk about the care of people who were dying.

And, so, I began to meet a few people nationally. Kathy Foley definitely was sort of a mentor from afar. Nessa Coyle, who was the nurse who worked with Kathy starting the pain program at Memorial. These were some of my earliest mentors. And then just sort of beginning to meet like-minded people through the Oncology Nursing Society, for example. I would meet nurses who were also working in oncology settings interested in pain but sort of -- it was really about palliative care.

And, so, I don't -- I can't even tell you whenever, the exact year. But whenever the Hospice Nursing Association started, getting involved with that through them. And then hearing about the Academy of Hospice and Palliative Medicine. And then those two groups began to have a joint meeting. So, that sort of connected me with both physicians and nurses in this new field of palliative care. So, I think those of us in this sort of first generation, we didn't have mentors because there weren't any, but we had each other. We started connecting with each other at professional meetings. And at least knowing there were other people around the country who
were trying to do the same thing I was trying to do in terms of bringing recognition to this care of people who were at the end of life.

Bryan Sisk: And I made the mistake of printing your CV without looking at how many things you've published first. And I see a number of things that you've written, obviously, about adult care. But I've also seen you writing some things about pediatric. So, what has been your kind of engagement with pediatrics and end of life and palliative care over the years?

Betty Ferrell: Yes. It's an interesting thing. Again, I can remember again in the '80s having just moved to California. And Elizabeth Kubler Ross had just done her work, her book that she had published about hospice care for children. That was my first recognition at all that there was any attention given to dying children. And I actually went to a lecture that she gave here in Los Angeles and was so moved by this idea that these same principles could be extended to children. And that, obviously, children had many similarities but also the incredibly unique needs of children. So, even though I've worked in adult settings and my research has been adult focused, I always had this interest in pediatrics.

I think two things really have influenced my commitment to pediatrics. The first is we started in the year 2000. So, this is our 20th year. We started the ELNEC project, that's the End of Life Nursing Education Consortium. We did a three-year planning grant from Robert Wood Johnson from 1997 to 2000, in which we tried to make the case of why there needed to be an ELNEC project. So, we surveyed nurses. We reviewed textbooks. We looked at nursing school curriculums. We did this broad needs assessment in order to make the case that we needed education for nursing. And, so that project was very inclusive. We were inclusive of both pediatric and adult care.

And, so, everything we did included pediatrics. And then in the year 2000, we then got the first funding to create the ELNEC project. At that time, we were overwhelmed with the task at hand. We had few resources and this huge task. And, so, we created one curriculum, one ELNEC curriculum. So, a one size fits all. And, so, we created this one curriculum and we were very intentional to include pediatrics in it.

The first three courses that we held -- so, we launched the courses in 2001. And by the end of that year, we had held three courses.
And, so, pediatric nurses and all kinds of nurses came to the ELNEC course.

And yet at each of those three courses, at the end of the course, the pediatric people would always come up to me and say, "Thank you for including us. We're thrilled to be here. We see where you've put pediatrics in. However, we really think there needs to be a separate pediatric curriculum." And, so, finally, after hearing this a few times, we didn't have any money. We tried and tried to get anyone to give us funding to do peds. Absolutely no one thought it was worth the work.

And, so, there's sort of a little humorous story about this -- by that point in time, we had funding left to hold one more course supported by the Robert Wood Johnson Foundation. And, so, what we decided to do is just do the work ourselves without funding to create the pediatric version. And then we would just set aside some of the money for that last course to bring together a group of pediatric experts and sort of pilot the pediatric curriculum and get it launched. And, so, we sort of -- the inside joke was Robert Wood Johnson funded the first pediatric course. They just didn't know they funded it.

And, so, that's exactly what we did. We pulled together 20 people. We created a curriculum. We brought them together. We did the first peds course. And then we had a room with 20 experts in pediatric care who then guided to refine the curriculum and sort of launch it. So, I think the critical was that, from the very beginning of my work with ELNEC—which is sort of three years of planning and now 20 years of operation—we've always been committed to pediatric care and thought to include pediatric care, although it was very hard to support that work.

And the other sort of influence for me is that prior to all of this, very early in my career—so, 1982. That would've been while I was in my PhD program. So, still in Oklahoma in my PhD program. I actually had a baby who was born prematurely, a son. And he lived for three months in a neonatal intensive care unit. And, so, this would've been during 1982. And he died in ICU.

I always -- sort of the way I best explain it is that we were in a hospital that had the most wonderful, kind, compassionate, amazing neonatal clinicians, physicians, nurses and others. And they had no clue in the world of what to do. And they really had no clue of what to do when it became apparent my son was dying. So, I lived through this sort of personal experience of having a child
die in acute care setting in which there was no preparation. There was nothing that would have provided the support that now, I think, we would all agree is the kind of care we would want for a child and family at their time of death. So, my commitment to pediatrics is both personal and professional. And, so, we have -- we launched our first pediatric course in 2003. And now, it's really been a great privilege for me to see this field evolve and to witness these dedicated pediatric clinicians come to the courses and go back and really inform systems of pediatric care.

Bryan Sisk: So, thinking a little more about the interplay of adult and pediatric hospice and palliative care. From your perspective, how much do you think that the development of this adult hospice movement and the Medicare benefit and all of that momentum. How much do you think affected the eventual development of pediatric palliative care?

Betty Ferrell: I think it was a huge influence in that if you look at the basic principles of hospice care, which originated in the adult world—basic principles like the family as a unit of care, quality of life and management of symptoms—are a high priority. Bereavement support is a component of good care. If you pick up like the earliest documents ever written about hospice in America, essentially everything about the philosophy, everything about what was being developed, you would say applies 100% to pediatrics.

However, we certainly know that the world of pediatrics is a very different world. We know that parents are going to seek every desperate means possible to prolong their child's life. We know that now, children live many, many years with serious illness before they die. We know -- there are so many things that we would say. All the principles are the same but it's still a really different world, that children are not little adults. Right? And, so, it's a different world. So, I think everything that I've done, that we've done in my projects. I think a broader field has tried to embrace that, the sameness and the difference. That the same principles apply and yet we -- there does need to be a separate dedicated effort in pediatrics to really serve this population as it should be served.

Bryan Sisk: Have there been any negative influences or any barriers that the adult field has created for the pediatric field?

Betty Ferrell: I think it's a barrier when anyone—adult pediatric policy maker, clinician—I think it's a barrier when anybody says, "Oh, here. Take this," and apply it to peds. So, to assume that one can just take the
adult world and lay it on pediatrics and think that's sufficient, that's a disservice.

A case in point would be, I think in the adult world, we often really emphasize issues of futility. Or the fact that there are times that our best care, our best course is really working very directly with families to withdraw life support for example or to avoid any life prolonging measures. But you can't apply that principle directly to pediatrics because the relationship of parent and child is a different relationship. And, so, I think is why pediatric palliative care needed to be developed by people working with children. Right? Only the field of pediatrics could develop pediatric palliative care. We can share common ground. We can -- we learn from pediatrics. Pediatrics can learn from adults. But it is a separate world and, therefore, we always need to realize that it is not simply a matter of taking something from the adult world and applying it to the pediatric world.

[00:32:01]

Bryan Sisk: So, from your vantage point, kind of right on that dividing line between the adult world and then dipping in pretty importantly into the pediatric world. What do you think was the real spark that drove the development of this as a specialty in pediatrics?

Betty Ferrell: I would say two things. One is that hospice programs did begin to try to serve children. And, so, there were a few pediatric hospice programs around the country that developed. And, so, that really advanced the knowledge of care at the end of life for children. And it also really advanced the idea of children leaving the hospital should die at home. So, the creation of pediatric-specific hospice was a huge contribution. But again, an example of how the pediatric world is different. We also know that many times, children will die in institutions, that it is the best thing for the child and the siblings and the parents to have that child in an acute care setting. And, so, it's been so important that institutions like St. Jude and Boston Children's and Washington National Children, the leading pediatric settings of care have modeled what palliative care looks like in the inpatient setting.

[00:33:35]

Bryan Sisk: As you think about your career looking back again, what do you think were the biggest challenges you hit as you were trying to develop this path that wasn't quite there yet?

Betty Ferrell: I mean there were enormous, enormous barriers that I would -- I mean I've been a nurse for 42 years and I would say easily the first 30 years were still a huge uphill battle and sort of a lone voice experience that people still didn't want to talk about death. People
still wanted to deny the patients would die. People thought this was not a priority. There was little funding to support this area. There was literally little infrastructure to support this area. So, really embracing palliative care as an important aspect of healthcare and having specialization, having physician training in palliative care, having nurse certification, having the Academy of Palliative Medicine and the Hospice and Palliative Nurse Association. Having the field formalized is still really quite new. So, I mean I would honestly say of my 42 years as a nurse, the first 30 years were incredibly difficult and mostly very uphill. And while we still have an enormous amount of work to do, I think it's only been -- I would probably be generous in saying it's only been the last 10 years that I feel like we've crossed the first peak of the mountain. I mean we've at least solidified some basics and are spending less of our time arguing that this is even a need. And more of our energy can now be focused on getting on with solutions. But it's still early.

[00:35:56]

Bryan Sisk:

So, over those last 10 years, what do you think have been the biggest changes in the care that we provide to people that are suffering and dying?

Betty Ferrell:

I think the development of pediatric hospice has been very important so that there is an opportunity for children to be at home and for death to occur at home, and to provide bereavement support for families and those kinds of things. I think probably the biggest influence has been the specialty of palliative care, the fact that we now have physicians in pediatrics who are board certified trained in palliative medicine. We have training programs. We have leaders. I think ultimately you can have a lot of structures but at the end of the day, it's leadership. And, so, I think people like Joanne Wolfe have lived the work and they've been people with such integrity and commitment that we have a model. Right? We can look to, "Wow, look at what she's doing." She's creating the field. Right? She's carving this field.

So, I think having national leaders, I think having models of care around the country. There have been some just beautiful examples of how death now happened in a neonatal intensive care unit. That happened because of people. Right? Dedicated people who have devoted their careers and dug in their heels and changed this sense of care. They said, “Children are going to die differently in our setting. Parents are going to be at the bedside. Parents are going to hold their children. They’re going to see the pain is relieved.”

So, I think having models, having programs because you can read about it all day but you need to be able to see it. And, so, having
models where we could see what palliative care looks like when it's happening has been critical. And having leaders, having real people committed to this field that can shape the field and influence others. And people need mentors. I never had any mentors. And, so, I think young physicians meet people in fellowship or early in their practice when they can go make rounds with Joanne Wolfe one day and your practice will be changed forever. Right? Go sit in on one interdisciplinary team meeting and see what it looks like when social workers and chaplains, nurses and physicians collectively plan the best care, and you'll never be able to practice the same way. Right?

So, I think you have to see it, do it and that's true especially when it comes to palliative care. So, I think I really credit the individual leaders in pediatrics for living the work, demonstrating the work while they were also creating the structure so that -- in palliative care, there's sort of many sort of the sayings -- one of the sayings is we've been building the plane while flying it. And I think that's particularly true in pediatrics. But Joanne Wolfe and there's many other amazing colleagues who have done this work. Pam Hinds was an early leader in nursing. There's many outstanding pediatric leaders now but they didn't wait till there was a textbook on their desk about pediatric palliative care. They didn't wait till there were national guidelines. They just got in there and started providing care to children. And, so, they were doing the work and living the work while they were providing the national leadership to create the field. And that's why care has advanced in this period.

[00:40:27]

*Bryan Sisk*: So, what do you think are the biggest challenges facing pediatric palliative care right now as a field?

*Betty Ferrell*: I think we still have huge health policy issues, reimbursement issues with the structures of healthcare, particularly reimbursement structures that still favor acute care intervention, prolonging life, disease-focused therapies. They still really lack the health policy changes. For example, while pediatrics has sort of done better than the adult world in terms of getting approval for concurrent care, children need to have the full benefit of hospice and palliative care while also continuing their disease-focused care. It's a great start but there's a heck of a long way to go in that area.

So, I think that we now have committed people. We have clinicians being trained in this work. We have structures. We have organizations. We have books. We have journals. But we still need health policy changes to make this become reality. So, I think
health policy and particularly health policy related to reimbursement are big continuing obstacles.

[00:41:50]

Bryan Sisk: I just have a few short questions left. But what do you think are the strongest pillars of the field? Not people but about the field in itself. What do you think is the brightest lights in palliative care right now for kids?

Betty Ferrell: I mean I know I sound like a broken record. I think the strongest thing we have going for us is that we have this cadre now around the country of dedicated leaders in this field. I'm a part of the Cambia Sojourners program, which is a project to now provide leadership to create leaders in the field. And, so, we've had several pediatric physicians. So, Debra Lotstein at Children's Hospital in L.A., Deb Lafond at Children's Washington are examples of scholars that are doing this work. Now, our biggest asset is that we have really smart, dedicated pediatric clinicians moving this field forward. That's the most important thing. I think the second most important thing is that we have structure. So, we have -- there's a coalition of the pediatric groups all committed to pediatric palliative care. That's a shared voice. Right? It's a strong voice.

I've been a part of the National Consensus Project Guidelines for Palliative Care, our guidelines for palliative care. And from the first edition of those guidelines, we have been inclusive of pediatrics. And, so, the fact that we have national guidelines inclusive of pediatrics for the field of palliative care. We have people, we have structures and processes in place. And we sort of have a growing public awareness. Right? So, there are many families who now can tell the story of how their child received good care. There are now many, many parents who can tell the story of how their child died in a different way than my son died. Right? So, those are the strengths. Those are the things that will continue to -- these efforts. But there's still a long way to go to fully adopt palliative care into education and practice. And there's big policy and public health factors that will need to continue to be addressed to fully realize the potential of pediatric palliative care.

[00:44:44]

Bryan Sisk: Of all of the things that you've done in your career, what's your favorite contribution that you've made to the care of children?

Betty Ferrell: I think without a doubt it's in our ELNEC pediatric curriculum. So, since we launched the curriculum in 2003, so that's been 17 years ago, we continue ELNEC pediatrics. We have an entire curriculum focused on pediatrics. We hold pediatric courses each year and our ELNEC pediatrics is a train the trainers. So, that means that we train our
out holding courses so there are hundreds of ELNEC pediatric courses held around the country in different institutions. And I think that having that curriculum and having that commitment has really promoted education nationally and internationally.

Our ELNEC budget, as of this year, we reached our 100th country. So, again, that's something we didn't plan but it just happened. And, so, 100 countries have now been trained in ELNEC and virtually everywhere that we've gone, the people start with the core curriculum, sort of the basics. But the second thing they always want is pediatrics because especially in developing countries where childhood mortality is still so high. So, in Africa and eastern European countries. I mean around the world, people really want the ELNEC pediatric curriculum because of childhood death and childhood illness.

So, I think without a doubt, our ELNEC pediatric curriculum I think has been -- has made a contribution and definitely, the ELNEC pediatric curriculum is only possible because of the dedicated pediatric clinicians that are part of it. Every ELNEC peds course is taught by leaders of the field. Vanessa Batista from Philadelphia, Amy Haskamp from Indiana, Cheryl Saxton from Texas. We have pediatric leaders who are teaching ELNEC pediatrics and it's these -- it's my pediatric colleagues who carry out ELNEC training. And, again, they serve as a role model. Gay Walker with Trinity Kids here in California. Again, living the work, caring for children, providing the first hospice care for children in this area. And, so, these are the people who teach ELNEC peds. So they can present the content in the binder but they can also tell the stories of the children they've cared for. And that's what, I think, really helps advance the field.

One last question. I'd really love for you to just dream aloud. So, with the budget and politics and the policy issues and everything we talked about. If none of those were obstacles, what would you ideally want care for these children to look like?

I would start with the fact that every clinician who's going to care for seriously ill children—so, every pediatrician, every pediatric specialist, every nurse who will work in any pediatric area—that those clinicians enter their practice, the first day they start caring for these children, that they have had education in palliative care. In ELNEC we always say, "You can't practice what you don't know." Right? So, if I want the pediatric oncologist or the pediatric neurologist or the pediatric primary care doctor or nurse to provide good pain management, offer good psychosocial support, do a
good spiritual assessment, offer bereavement support, then they can't deliver that care unless they were taught how to do it. So, in my ideal world, clinicians enter practice having had education in palliative care that prepares them for that role.

And then my dream is that all settings of care for children have incorporated palliative care that hopefully, in most larger settings, there's a specialized pediatric palliative care team or service. But more so, that the principles of palliative care, we now refer to it as the palliative care generalist. That if you're a pediatric neurologist and you're going to spend a lot of your time caring for kids with brain tumors, how can you possibly do that work without having good palliative care knowledge? Right? If you're a nurse practitioner and you work in oncology administering chemotherapy to children with cancer. How could you now provide good palliative care? And, so, we need people to enter practice knowing palliative care and we need structures in every facility that cares for seriously ill children so that it's built into the system, that these children and their families get good care. So, palliative care needs to be a part of all pediatric care to be accepted. It should not be the exception.

[00:50:07]

_Bryan Sisk:_ Those are all the questions I have. Are there any other areas of this history that you feel like I haven't gone in depth in or I need to dig more into in the future?

_Betty Ferrell:_ I don't think so. I think we've kind of covered it. And I'm sure you're talking to lots of pediatric specialists who have a deeper knowledge than I do in many aspects of the care. So, I'm sure you're going to get so much good information.

[00:50:47]

_Bryan Sisk:_ Great. Well, thank you. I'm going to stop recording.

_End of Recording_