Betty Davies Oral History.

Follow this and additional works at: https://digitalcommons.wustl.edu/ped_pal_oral_hist

Recommended Citation

This Article is brought to you for free and open access by the Oral History at Digital Commons@Becker. It has been accepted for inclusion in Pediatric Palliative Care Oral History Project by an authorized administrator of Digital Commons@Becker. For more information, please contact vanam@wustl.edu.
Biography

Dr. Betty Davies, RN, BScN, MN, PhD., devoted her fifty-year career to the international development of death, dying, and bereavement practices in pediatrics. Dr. Davies is an Adjunct Professor and Senior Scholar University of Victoria School of Nursing and Professor Emerita of Family Health Care Nursing at the University of California, San Francisco. She is a co-founder of Canuck Place Children's Hospice, the first free-standing pediatric hospice in North America. She has published over 100 articles in refereed journals, been reported in approximately 200 publications, held leadership roles in multiple organizations addressing death, dying, and bereavement, authored over 40 book chapters in addition to 3 books and 6 co-edited books. Dr. Davies has retired twice, and is now officially retired, but continues to be active in research, presenting, and mentoring.

Interview Abstract

Dr. Betty Davies begins with several stories about her first dying patients as a young professional and the gaps in both her education and the humanity about how death was handled in the hospital setting. Dr. Davies felt that cultivating dialogue about death, dying, and bereavement was a very important “human activity,” that was being neglected. Early into her career, Dr. Davies connected with other likeminded professionals who supported her while she endeavored to give trainings and workshops. She then recalls her work in developing Canuck Place as well as her contributions to research, programs, and the international knowledge base for pediatric palliative care. Dr. Davies explores some of the challenges she faced in her career as well as her perspective on how the field has grown. She concludes with her dream for seamless and continuous care to be available to children in need of pediatric palliative services.
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td>Association for Children's Palliative Care</td>
</tr>
<tr>
<td>ALL</td>
<td>Acute Lymphoblastic Leukemia</td>
</tr>
<tr>
<td>ChiPPS</td>
<td>Children's International Project on Palliative/Hospice Services (Now known as NHPCO’s Pediatric Advisory Council)</td>
</tr>
<tr>
<td>ENT</td>
<td>Otorhinolaryngology; Ears, nose, throat</td>
</tr>
<tr>
<td>ICU</td>
<td>Intensive Care Unit</td>
</tr>
<tr>
<td>ICPCN</td>
<td>International Children's Palliative Care Network</td>
</tr>
<tr>
<td>IWG</td>
<td>International Work Group on Death, Dying and Bereavement</td>
</tr>
<tr>
<td>NHPCO</td>
<td>National Hospice and Palliative Care Organization</td>
</tr>
<tr>
<td>NICU</td>
<td>Neonatal Intensive Care Unit</td>
</tr>
<tr>
<td>NINR</td>
<td>National Institute of Nursing Research</td>
</tr>
</tbody>
</table>
Interview Roadmap

Beginnings

Personal career influences.................................................................1-6, 10-13
Colleagues, mentors, mentees, and other influential figures .......... 5-9, 15-16, 18, 20-25, 27

Pediatric palliative care

Evolution and history of pediatric palliative care ......................... 1-5, 13-14, 17-19, 22-24
The dying patient and bereavement ..................................................3-6, 21-24
Publications, trainings, organizations, research, and funding............6, 17-19, 22-25
Canuck Place ..................................................................................15-17, 20-22, 24, 26
Pain and symptom management .......................................................5, 8-9, 13-15, 22
Reframing professional practices.......................................................6-7, 11, 14, 26
Successes..........................................................................................4, 13, 23, 27
Challenges .......................................................................................10, 13-14, 17, 22-23, 25-27, 30
The future ..........................................................................................27-29

Relationship to adult palliative and hospice care

Parallel journeys...............................................................................1, 17, 20-21, 24, 27, 29
## Related Works and Mentions

<table>
<thead>
<tr>
<th>Mention</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>A Grounded Theory</em></td>
<td>8</td>
</tr>
<tr>
<td>Benoliel, Jeanne Quint</td>
<td>8, 9</td>
</tr>
<tr>
<td>Binger, Charles</td>
<td>21</td>
</tr>
<tr>
<td>Bluebond-Langner, Myra</td>
<td>23</td>
</tr>
<tr>
<td>Chappell, Beverly</td>
<td>24</td>
</tr>
<tr>
<td>Corr, Charles &quot;Chuck&quot;</td>
<td>8, 9, 17</td>
</tr>
<tr>
<td>Dominica, Sister Francis</td>
<td>20, 22</td>
</tr>
<tr>
<td>Eng, Brenda</td>
<td>15</td>
</tr>
<tr>
<td>Glaser, Barney</td>
<td>8</td>
</tr>
<tr>
<td>Goldman, Ann</td>
<td>23</td>
</tr>
<tr>
<td>Griffiths, Arthur</td>
<td>16</td>
</tr>
<tr>
<td>Jarvis, George</td>
<td>16</td>
</tr>
<tr>
<td>Kramer, Robin</td>
<td>21, 22</td>
</tr>
<tr>
<td>Kübler-Ross, Elisabeth</td>
<td>5, 6, 7, 8, 15</td>
</tr>
<tr>
<td>Lamers Jr., William &quot;Bill&quot;</td>
<td>9</td>
</tr>
<tr>
<td>Levetown, Marcia</td>
<td>17</td>
</tr>
<tr>
<td>Liben, Stephen</td>
<td>18, 27</td>
</tr>
<tr>
<td>Limbo, Rana</td>
<td>24</td>
</tr>
<tr>
<td>MacDonald, Neil</td>
<td>24</td>
</tr>
<tr>
<td>Martinson, Ida</td>
<td>9, 15, 20, 23</td>
</tr>
<tr>
<td>Mount, Balfour</td>
<td>6, 9, 23</td>
</tr>
<tr>
<td>Moulinier, Francesca</td>
<td>5, 8, 15</td>
</tr>
<tr>
<td>Papadatou, Danai</td>
<td>24, 27</td>
</tr>
<tr>
<td>Parks, Colin Murray</td>
<td>9</td>
</tr>
<tr>
<td>Schuurman, Donna</td>
<td>24</td>
</tr>
<tr>
<td>Sourkes, Barbara</td>
<td>18</td>
</tr>
<tr>
<td>Spinetta, John</td>
<td>22, 23</td>
</tr>
<tr>
<td>Strauss, Anselm</td>
<td>8</td>
</tr>
<tr>
<td><em>The Oxford Textbook of Medicine</em></td>
<td>24</td>
</tr>
<tr>
<td>Waechter, Eugenia</td>
<td>23</td>
</tr>
<tr>
<td>Wagner, John</td>
<td>5</td>
</tr>
<tr>
<td>Wald, Florence</td>
<td>9</td>
</tr>
</tbody>
</table>

**Edited for grammar and content by Dr. Davies. Additions and redactions indicated by brackets and ellipses, respectively.**
Today is June 13, 2019. I am Bryan Sisk and I am in St. Louis, Missouri, interviewing Dr. Betty Davies over the telephone for the Pediatric Palliative Care Oral History Project. Dr. Davies is in Victoria, British Columbia. Thank you, Dr. Davies, for joining me today. To get us started, can you tell me when your mind turned towards pediatric palliative care as your focus?

Well, yes. It's not that easy to describe because, as you know, I'm a nurse and I wanted to be a nurse ever since I was a young child. Not only did I want to be a nurse, I wanted to be a pediatric nurse and I also wanted to teach nursing from as far back as I can remember. My interest in pediatrics was always there.

When I went into nursing school, which was quite a few years ago, I had an experience with an adult patient and then experiences with children that made me realize what little regard there was for teaching about and doing clinical work with patients who were dying. The situation I'm talking about is one that I've talked about many times, trying to make my point [about the importance of students being guided in learning about death]. It was caring for a woman whose name—I called her Mrs. Jones. I was a second-year nursing student.

I was on a week—back in the days when we nursing students worked in shifts and weekends and mostly ran hospitals—I was on a respiratory unit caring for this woman who had cancer of the lung. Many of the patients on that ward at that time, had cancer. During night report, the night nurse said that she was surprised that Mrs. Jones had actually made it through the night because she was doing so poorly. I remember sitting there in report, thinking to myself, "Oh, God. Please, let her make it through the day," because I honestly didn't know what I would do if Mrs. Jones died. We had had no instruction, up to that point, about what you do when someone dies.

We finished report and I stayed behind to get myself organized because the hospital that weekend was very short staffed due to a flu epidemic that was affecting many of the staff and many of the patients. Meanwhile, the one other person who was working on this team with me was a nurse's aide. The nurse in charge was the only other staff member there to care for 32 patients. I stayed behind to get myself a bit organized.

The nurse's aide went to quickly check on the patients, came back, and said to me, "I think you better look at Mrs. Jones." I went
down the hall, I went into the room, and just looking at Mrs. Jones, I realized that she had died. I didn't know what to do. I had once seen in a TV show, where the nurse went in and lowered the head of the bed of the patient and drew the curtain around. That was the only reason I knew what to do.

So, I did that and then I went back to the nurse's station, and I said to the nurse in charge that "Mrs. Jones had died." Of course, my voice was squeaking and my knees were weak. I just didn't know what else to do. She was on the phone taking medication orders from a physician. Without looking at me, she simply whispered to me and pointed, "The procedure book is there on the shelf," which meant get the procedure book, look up what you're supposed to do and go about doing that.

Luckily, she had the good sense, to call Nursing Office so they could send a few people to help us. They sent one of my nursing buddies, who also was a second-year nursing student. We went into Mrs. Jones' room with the mortuary basket and the list of things that you're supposed to do and we proceeded to do them; however, neither of us had ever seen a dead person, had ever thought about a dead person really, and had no idea what to do. I was the one who was going to wash Mrs. Jones because the first step is to gently bathe the patient.

I put my hand in the water, rinsed out the cloth, twisted it around my hand like nurses learn how to do so water doesn't drip all over the bed and the patient, and I went to touch Mrs. Jones and my hand would not go there. It just started to shake. I pulled it back, I put it back in the water, and tried a second time. This time, the end of the washcloth fell out and dribbled everywhere. As is often the case when people are close to tears [laughs] and realizing that they're in a difficult or ridiculous situation, they laugh. My friend and I began to giggle.

Then we realized that was inappropriate, so we stopped and tried again. The third time, I was able to touch Mrs. Jones. My other hand—my free hand—accidentally touched her thigh and she was still warm. I remember exclaiming to my friend, "Oh, my gosh. She's still warm!" I had the idea that when people died, their bodies became cold. I didn't know that it took a little while for that to happen.

So, we went on. We bound her wrists together so that the arms don't flop when the patient is being transferred, and we managed to tie the gauze too tightly around her arms so that we couldn't get the
cotton batten in that you're supposed to put between the wrists in order to prevent them from bruising. Things like this happened; one after the other. We vacillated between crying and laughing. We finally finished. What would take an experienced nurse 10, maybe 15 minutes to do, took us an hour.

We finished, checked off our list, made sure everything was in order, and then we realized that Mrs. Jones actually was in a four-bed unit and all of this that we had been doing and saying and all the noises we'd been making was in front of three other patients. Well, two of the patients were elderly women, as was Mrs. Jones. They had no idea what was going on because they were just very confused, little old people. However, the person who was foot to foot with Mrs. Jones' bed was sitting cross-legged. She was about 70 years old.

She was sitting cross-legged on her bed with her elbows on her knees and her chin on her hands, with her eye on the curtain. When I went to open the curtain, at the crack in the curtain, I looked out and I had direct contact with her eyes. She simply opened her arms and said to us in a very sensitive voice, "First time, isn't it?" At that point, we both went over, sat on the bed with her arms around us, and we cried because we were—it was just so stressful as young people, having that be our first experience [with death].

So that got me very interested in what happens when patients die because, clearly, we'd had no instruction. The head nurse was very insensitive in terms of her response: "Go look it up in the procedure book," doesn't seem to be—I mean, it got the job done, but it's not the way people should communicate about these things, in my view. From that point on, I cared for many dying patients because when I went to each new unit as a student in my clinical rotations, it seemed like all the instructors knew that I'd had this experience.

Years later when I became an instructor, I realized that just as students go off to their coffee table and talk about what's happened to them during the day, so do the instructors. My instructor didn't work weekends, but when she got there Monday morning, she heard about what had happened to her student and then she talked about that to other instructors and on it went.

I would often get assigned to the patients who were dying because the instructors thought that I'd had experience with that and, therefore, I would be able to handle it; however, I later realized the reason they did that was because they didn't then have to face
dying, themselves. Nor did they have to help other students with the whole issue of dying. I merrily went on my way, being very curious about why doesn't anyone talk about this? Isn't anyone else interested in what happens in these situations?

I could hardly wait for my clinical rotation to pediatrics because that was where my heart was. Of course, back then—this is like the late 60s—back then, many children on the regular pediatric floor were children dying from cancer; leukemia, especially. ALL took the lives of 90 percent of the children back then, as compared to now; it's 90 percent who survive. It's quite remarkable, the difference over those years.

Anyway, I had experiences on pediatrics like caring for a little girl whose name was Susie. She had a leukemia and she had the red blotches and red spots over her little body. She was four years old. Somewhere along the way, she had been given a stuffed toy that was a frog. He was green and he had red spots on him. Of course, that was her favorite toy and she held him in her hands. As I was washing her, giving her, her morning bath, she says to me, "You know," she called him Froggy, "Froggy has spots," and I said, "Yes. He does." "He has spots just like I do," "Yeah. He does." She said, "You know why those spots are there?" I asked, "Why would that be?" She replied, "Because he's sick. He's really sick and he's not going to get better."

I thought, "This little girl knows that she's not going to get better." Before that—I mean, up until even after that time, people believed, based on the work of Piaget, that children did not develop a mature concept of death until they were at least nine years old. No one would ever talk to children about death. No one would ever talk to them about how sick they were, because people assumed that the children didn't know what was going on.

Well, you know as well as I do that when you work with children, that children are pretty smart [laughs], and they know a lot before they're able to verbalize anything. I thought, "Okay. This little kid knows she's dying. Why doesn't anyone else seem to get that message from her or listen to her?" It kept happening over and over. Eventually, I became really interested in dying children and I had other experiences like a child—when I was a staff nurse, a little baby was born with a [large, inoperable tumor under her chin]. She was basically just left to die. Her physician came and checked on her regularly, but she wasn't given any pain medication. She was just allowed to die. Now, in some ways, it was a very kind death and it was peaceful because she simply went
to sleep, but it was all very secretive. She was kept in the room close to the nurse's station, but nobody ever went in, except for the physician and me.

In caring for adult patients, I found that they were always at the end of the hall and nobody wanted to talk to them. Many, many clinical experiences like that got me interested in how children die, how people die in hospitals, and why doesn't anyone ever talk about it.

I went to University of Arizona to do my master's degree. While I was there, I met a woman who was my clinical preceptor in my clinical portion of the program. Her name was Francesca Moulinier.

Fran was a head nurse but worked more as a nurse practitioner clinician. She was also interested in effective communication with dying children, and in communicating with their parents. She had many experiences to share about her work with Mexican-American families, some of the cultural beliefs, and stories about how Mexican people interpreted [events surrounding dying and death.]

Well, one of the most important things she did for me was that she went with me a to a conference in Chicago where she had met previously and then introduced me to Elisabeth Kübler-Ross. We went to visit Elisabeth in her home. When I graduated with my master's degree, I became a head nurse on a pediatric unit at St. Mary's Hospital in Tucson. I met a physician, John Wagner, who was an ENT specialist. I also met the hospital chaplain.

The three of us, somehow—I don't remember how, exactly—discovered that we were all interested in dying children. As an ENT specialist John Wagner had had a patient, [Ermalinda,] with a malignant tumor in her maxillary joint and the maxillary bone. The tumor had spread rapidly and she died from it. It distressed him very much because, even as an accomplished, experienced physician, he had no idea how to deal with this girl’s impending death. He had not had any training in his medical education about death. He had not had any experience with death because most ENT specialists, of course, [seldom have patients with terminal diagnoses.] The three of us set up a committee called the Quality for Life committee—not of life but for life—where we volunteered to talk to patients, family members, and staff about any experiences they were having about death and dying and bereavement. That led to a whole other train of experiences with Elisabeth as our consultant. Elisabeth loved to come to the desert,
so she came every six weeks or so because she had a contract in Phoenix. [So, every six weeks, the three of us would drive up to Phoenix and meet with her for a consultation about what we were doing, what else we might do, and our own reactions to what we were doing. My interest in dying children and their families continued from my clinical work. I did not yet know about the new term, “palliative care,” that was coined in 1972 by Dr. Balfour Mount, a Canadian physician in Montreal, after he visited St. Christopher’s Hospice in London and decided to adapt that hospice concept to in-hospital care. It was during this time at St. Mary’s Hospital that my interest extended to siblings of dying children and bereaved siblings.]

I subsequently returned home, back to Canada, to Edmonton and to the University of Alberta where I'd gone to nursing school and where I was now teaching. [Through Continuing Education at the U of Alberta,] I offered workshops to the community on Coping with Loss. I felt that learning about death, talking about death, was an important human activity that nobody seemed to pay attention to.

[Then, I went to the University of Washington where I did my Ph.D. I studied bereavement in siblings up to three years after the death of a child from cancer. I finished my dissertation in 1983. In 1986, I did post-doctoral study with Dr. Ida Martinson where studied sibling bereavement at 7-9 years post death.] … When I thought about the question that you were asking about what turned my mind towards pediatric palliative care as a focus, it really—it evolved from my experience, starting way back from when I was a student…

That's a very long answer to your question [laughs], but those were the thoughts that came to my mind when I thought about your question because it wasn't like I chose early on to think, "Oh, I think I'll go into this specialty," as many people do, today. Back then, it just came about by itself, really, [from my curiosity about dying and bereavement.]

When you were starting out, you talked about how you were able to find some people locally, some people, nationally—Kübler-Ross—who were like minded. Were you able to find, outside of that small group, another community of people with similar minds on this?

Not at first, no. It was very hard to find people who really shared my interest. The example of my nursing instructors and how they
handled one student's experience of caring for a dying patient—or a dead patient, really—I think, represented what the reaction was, oftentimes, to my interest about what happens how and when patients die. Why aren't nurses and doctors interested? Why does nobody talk about this? Why aren't we, as students, being taught about this?

The reaction of the nursing instructor was indicative of the society's general attitude toward death, which was, "Don't talk about it." Still, in many cultures like the Chinese culture, for example, people believe that talking about or mentioning death or the fact that someone might die brings bad luck to the person who is ill or to the people you're talking about, so they prefer to avoid the topic. When working with Chinese people, we've had to figure out ways of talking about it without mentioning the word because it's the word that brings the bad luck; not so much the concept that someone is dying.

It was really lonely back then. And, when I stopped to reflect on what I learning in nursing school, [I realized that death is integral to nursing. We were taught] that nursing is about three things: It's about how to prevent illness so people can stay healthy. When people get sick, it's about caring for them until they get well. When they don't get well, it's about helping them die with dignity. I thought, "Okay. We've been taught that these are three major goals of nursing.” But, as students, our focus was mostly on the care of the sick.

We focused very little on preventative health, which has grown over the years, but back then it wasn't a strong focus. There was nothing about care of the dying except this page in the procedure book about what to do with the body after death. It just seemed puzzling. Then, I met Francesca and we just had—we're still really good friends because we shared this interest. We even gave workshops together and then, to be introduced to Elisabeth Kübler-Ross at that time was like a godsend.

Now, Elisabeth’s popularity has waned a bit over the years, but her description of the five—what she called the five stages of anticipating death—was based on her conversations with people who were dying. She was not studying people who were grieving [the loss of a loved one.] She was one of the first to make that distinction, but somehow, [the idea has carried over and persisted as the five stages of grieving]. In fact, Chuck may have told you about the article he's just written about how the work of Kübler-Ross fifty years later is still prominent in writing, teaching, and in
all sorts of guidelines for grief and bereavement, when it's actually quite out of date.

Meeting people like Elisabeth, at the time, I found her quite inspiring—[I found her to be a] very concerned person and a very good mentor for me.

When I went to do my Ph.D. at the University of Washington, and studying sibling bereavement and I had a professor named Dr. Jeanne [Quint] Benoliel. In the late 60s, you probably know that Glaser and Strauss were also interested, though I didn't know them at the time, in what it was like to die in hospitals. They conducted an extensive grounded theory study [that formed the basis for their book, *Awareness of Dying*, published in 1965.] Well, Jeanne was a doctoral student at the time and she worked with Glaser and Strauss as a research assistant. She analyzed the data about nursing care of the dying and wrote the first nursing textbook on care of the dying. [The book, *The Nurse and the Dying Patient*, was published in 1967.1] Because of her interest in death and dying, Jeanne was on my dissertation committee and I benefitted from her wisdom.

[Upon completing my doctoral degree, I returned to Alberta where] I had a newly formed joint appointment position between the University of Alberta Faculty of Nursing and the Cross Cancer Institute. [My role as a Nurse Researcher was to stimulate] interest in nursing research - because that was another field that was beginning to develop [under the auspices of the Alberta Foundation for Nursing Research. One aspect of my role was to organize the annual research conference – previous conferences focused on adult care and I decided it was time that they had a guest speak about children with cancer. I invited Dr. Ida Martinson who had developed the first homecare program for children with cancer and showed that such care was not only feasible but also had positive outcomes for the children, their siblings, and their parents.]

Meeting Dr. Martinson was finding another like-minded person. She invited me to come and do post-doc work at UCSF [University of California at San Francisco], which I did. I continued with my study of sibling bereavement and pediatric-related palliative care. [Ida, along with Jeanne Benoliel, were] members of the group that Chuck may have told you about—the International Workgroup on Death, Dying, Bereavement. This is a group of professionals – clinicians, researchers, educators - who, by invitation, come

---

together to share their demonstrated expertise in death, dying, and bereavement. At that time, compared to them, I didn't have much demonstrated expertise, [laughs], but Ida and Jeanne invited me, and I was accepted as a member. That's how I met and became colleagues with people like Chuck Corr, Colin Murray Parkes, Balfour Mount, and many others from around the world who were well known for their work in death, dying, and bereavement and palliative care. Bill Lamers, who established the Hospice of Marin beginning and he also was the one who developed the particular cocktail medication for people who were terminally ill and needed pain management. Florence Wald, who started the first hospice in the U.S. in New Haven, Connecticut. That's when I felt like I had finally found people who [laughs] I could talk to without them drawing back or saying, "Oh, my! That must be difficult," or, "What on earth would make you interested in death?" [laughs] After a while, that response gets kind of old. It was in IWG that really feel that my interests were okay and that I belonged to at least one small group of people who shared that interest.

Since that time, of course, the field of palliative care has expanded and in many ways, [including the field of pediatric palliative care.] I feel part of the pediatric palliative care community, from which I take great enjoyment and encouragement. Even though it's a small group but I feel I have a home, you know? It was hard to find people of similar interest because they just weren't there at first. Then, as I learned later, this group of people in IWG was there and I got to know them and felt like there were more and more people interested in this field. I'm sorry. I talk on and on and on [laughs].

Bryan Sisk: No that's wonderful.

Betty Davies: That's how I found people with similar minds.

Bryan Sisk: You talked a little bit about this, but could you tell me more about when did you first feel comfortable telling your colleagues that, "I'm really interested in this." Was that something that you felt comfortable from the beginning or is it something that you grew into over time?

Betty Davies: No. I think I was comfortable with it from the start because I was so curious about why nobody else was interested [laughs]. I didn't feel uncomfortable; it's just that I felt—I can't say I was really lonely, really. I was just curious as to why no one else was interested in this. So, I just kept following my own little path and eventually joined up with other people.
My interest started, like I said, when I was a student because I had cared for so many children who died - children [with cancer and other conditions that used to be called “genetic conditions. Such children] died more frequently back then than they do now. I am just grateful, I guess, for having more people in the field, now. Also, as I met other people who were as interested as I was, then that just was encouraging and reinforced my interest. I'm not sure that that answers your question exactly.

Bryan Sisk: I wanted to dig into a little bit of the on-the-ground reality from when you were training in the hospitals from being a nursing student to your nursing work. I guess that'd be, probably, the late 60s, I guess, when you were starting out?

Betty Davies: Yeah. I graduated with my BSc in 1970, so I was a student in the late 60s and went on after that.

Bryan Sisk: When you were beginning all of that work, what do you think were the biggest challenges in caring for these children that were suffering and dying?

Betty Davies: I think one of the biggest challenges that I saw was that people didn't—at the very beginning, people didn't talk about it. It was this big secret and people were distinctly told—like you mentioned, healthcare providers were told not to talk about it because it was too upsetting for parents. One of my favorite stories makes that really clear. It was the story of a little boy whose name was Scotty.

He had leukemia and this was in my early career—I was a combined staff nurse and clinical instructor on pediatrics and dealing with the children who were zero to eight...

I always wanted to be a pediatric nurse and a pediatric nursing teacher. I vowed, from a very early age, that if I ever get to be the teacher I want to be, never will I have a student who passes through my hands without a discussion about death and dying. I've been talking about this for years to students because I was just so concerned— students should not be exposed to their first experience with death in the way that I was. That's just not the way to teach students, or anyone, about sensitive topics.

Scotty was eight years old, had leukemia, and he was on our unit. His parents did not want—definitely did not want anyone to tell Scotty how sick he was. We were not to mention it. His parents
were adamant about that, and the physicians and nurses agreed to support them in their wish.

Now, in this day and age, if parents were that adamant, the nurses and doctors that I know in palliative care would sit down with them and really explore the reasons why they feel that way and how else might they give optimal care to Scotty and how might we all work together on this? Back then, it was, "Okay. That's what the parents want. That's what we're going to do." My own, personal belief is that the reason back then that healthcare providers were so willing to prevent any conversation or to allow no conversation, is because they themselves didn’t want to talk about it, either. Talking about dying and death is too scary. They don't know what to say.

Scotty lived quite a ways outside of the city and his parents were not able to be with him all the time. He went home for special occasions. It was Thanksgiving and on the day before Thanksgiving, his grandparents came to take Scotty home for Thanksgiving. They had just gotten on the elevator—I saw the doors closing and I ran to catch it and slipped in between the doors. There stood Scotty and his grandparents.

I looked at Scotty and said, "Hi, Scotty. I bet you're going home for Thanksgiving dinner." He says, "Yup!" with a big smile on his face. I wagged my little finger at him and said, "Now, I want you to not eat too much turkey this weekend," and he said to me as clearly and as forthrightly as he could, "Why not? I won't be here for the Christmas one." It took my breath away. I thought his grandmother was going to faint on the spot. They left the hospital and his parents brought Scotty back from that weekend.

They called for a meeting with the physician and the nurses who were caring for him and since I was his primary nurse, I was there too. His parents made it very explicit that “obviously” someone must have talked to Scotty because of what he had said, and did we not understand that we were not to talk to Scotty about this? They left for home. Scotty’s condition is getting progressively worse. He's in isolation now because his white blood count is way off. There are two beds in the room because it's usually a semi-private room.

Scotty shows me his stuffed animal, a long snake, that he had brought back with him. He named it Super Salami. Super Salami occupied the second bed. Every time someone came into the room to do something, they had to do it to both Scotty and to Super
Salami. The lab technician took blood from them both. The physical therapist came in and treated both of them. The physician had to talk to both of them, and as a nurse, I had to care for both of them.

I'd given Scotty his morning bath and then I was sitting on Super Salami's bed, stroking him gently with the washcloth and Scotty says to me, "You know, Super Salami is really sick."
"Is he?" I said.
"Yeah. He's really sick."
"Oh."
"He's not going to get better."
"Oh. He's not?"
"No. He's not."
A pause, and then Scotty said, "What do you think is going to happen to Super Salami?" I still vividly remember that moment.

I think, "What do I say? How do I deal with this?" Because our conversation was about Super Salami, I picked him up and I held him in my arms and I said, "You know, Scotty, I can't tell you for sure what's going to happen to Super Salami, but I know that wherever he goes, someone will be there to love him."
It always brings back so many emotions from that time. Scotty looked at me and said—without a whimper, a sigh, or without any apparent surprise,—he said, "Oh! You know what? That's what I thought."
I thought to myself, "Why didn't I ask Scotty what he thought?" It was just such an incredible moment.

I often tell that story because it's very meaningful. It talks about how children know what is going on, but if adults don't allow them to express what they know or even talk to them and explain what's going on, children find their own ways of figuring things out and not necessarily the best ways.

Just an interesting footnote to that. I mentioned that I gave workshops for quite a few years on coping with loss and death. One time at one of my workshops, a participant happened to be Scotty's aunt. I told that story and this woman [seemed agitated. During a break, she came to me and introduced herself and] she said, "I can hardly wait to go home and tell his mom and dad about what you've just said because that will make them so happy to know that Scotty was at peace with the fact that he was going to die."
In the end, even though his parents, who didn't want anything said about Scotty’s prognosis, could value the fact that Scotty did know and maybe there would've been a different way of handling the situation. But, at the time, they did the best they could. Anyway, that's how it was, then. I hate to say it, but in the hospitals today, even on pediatric units, there's still some of that attitude; particularly, in ICUs because that's where [the focus is on ensuring the childrens’ survival, on giving them life and it’s hard to have children, and babies in NICU, die.]

One of the joys of pediatric palliative care, in the hospice in particular, is that conversations about death are commonplace. Hospice is where you're helping people live while they're dying, recognizing that dying is part of living. [So talking about dying has changed remarkably in many ways, but I think it was] one of the biggest challenges. The other challenge had to do with how pain was treated. Well, you know it's pretty hard to treat pain when you don't think children have any. Which is what people thought for quite some time.

It used to be, when I started nursing, that when baby boys were to be circumcised, they were [strapped to a board for] the circumcision to take place. Those poor little creatures would scream their lungs out and we were all told that was because they didn’t like being restrained. No. They don't have much pain. Well, it took a lot of years for clinicians and researchers to study pain and realize that children, even newborn babies, [experience pain. To help children communicate about their pain, a pediatric nurse, Donna Wong, was the first to develop the Faces Pain Scale.]

Understanding pain in children became common knowledge and then, as a result, treatments began to change. Sometimes, I say, "Oh, gosh! My stories are from the Dark Ages." Well, literally, they were from the Dark Ages because no one knew then what they know now. It's not that people were bad; it's just that they didn't know, and they didn't seem to have the common sense to think that, "maybe the reason these children were crying is because they were in pain." Anyway, curiosity is sometimes not evident when it should be.

**Bryan Sisk:** How do you think clinicians at that time, whether doctors or nurses or whatever—how do you think they understood the suffering of these children? Did they focus on individual symptoms? Did they, at some point, start to have more of a holistic view of what suffering might be?
Betty Davies: I would say that the focus then—as it often is today, I'm sorry to say—is on treatments, on adhering to protocols, on following procedures, and fixing whatever the condition or the diagnosis is. We have been taught to identify the problem and then attend to it, or fix it. That becomes the central focus. [If pain is the problem, we do x. If it’s nausea, we do y. There is nothing wrong with this; it's a proven path to much success. But, there is relatively little attention to looking at the patient as a whole person with] psychosocial needs, for example, depression, anxiety, fear—and suffering. However, there were always exceptions but the exceptions were in individuals; not in programs or it wasn't generalized—it wasn't common among clinicians, as a whole.

Then as you were going forward in your career, what were the biggest challenges you personally faced, as you were trying to forge this career in an area that most people weren't aware of or were uncomfortable with?

Betty Davies: What are you asking? I think you are asking what were the challenges?

Bryan Sisk: Did you meet resistance as you were trying to develop this career or were there other challenges that you faced as you were developing your individual career?

Betty Davies: I think meeting Francesca in Arizona, my advisors in my graduate education, and Kübler-Ross, and Ida Martinson [who became my post-doctoral supervisor] all helped considerably in helping me with the challenge of feeling somewhat “different” in my chosen field, though I never questioned my choice.] Then, in IWG, I felt as though I was part of a cohort of people who were really interested in changing the ways people thought about illness and death and loss and suffering. I found people of common mind, and so that made it much easier.

When I think of people who are trying to establish pediatric palliative care for children in other parts of the world, I see that they have many challenges. In parts of Africa, for example, there's not even enough morphine to give children to manage their pain, so of course, attending to the physical need becomes priority. [No matter the location though, palliative care practitioners focus on doing all they can] to deal with the immediate physical symptoms and find ways to manage them. [Many healthcare providers seem to get] so caught in trying to do that, that it's hard to step back and look at the whole picture, which involves a slightly different focus.
A broader focus and a different way of communicating about what they're doing and what they're trying to do.

In pediatric palliative care, per se, we had some challenges in developing the hospice. The hospice evolved out of the interest of my colleague, Brenda Eng, who was interested in care of children who were dying, and myself, who was interested in the psychosocial aspects of care and children's bereavement. Specifically, how do we handle children and their siblings during the child’s illness and after the child’s death so that those siblings have a more positive than negative experience?

Brenda and I put together a Steering Committee of eight or nine people, including a pediatric oncologist, a social worker, a child life worker, some parents, [and ourselves, and the work of that committee resulted in the development of] Canuck Place Children's Hospice. We had lots of enthusiasm and we put a lot of effort into [the project, and at some point, we realized that such a project requires funding. But, our group of people was] not rich; none of us. Nurses and social workers tend not to be wealthy; pediatric oncologists don't do too well at it, either. We didn't operate in circles of wealthy people. We realized we needed help in marketing what we were doing, so that we could attract funding.

We looked up some public [relations firms and contacted three of them. A representative came] from each firm to talk with us about what kind of work their firm did, how they did it, and how they could help us in doing what we were trying to do. [All of them expressed great interest in our project but all three had the same bottom line:] "Well, you know you have to spend money in order to make money," which, to our little group of “poor” [volunteers, their $10,000 fee was impossible.]

[However, through those individuals, George Jarvis heard about our project. George himself was a partner in another PR firm and he had reached] the point in his life where he said he had had “enough” of that. He wanted to retire and do something more useful, more humanitarian. He approached Brenda to say he would like to help us. [And, George know all the right people who could potentially help us, such as] Arthur Griffiths, who, at the time, was the owner of the Vancouver Canucks hockey team. The Vancouver Canucks had a children's foundation and they [“adopted” our project and were our chief source of financial support. Ray Loewen, owner of a string of funeral homes at the time, donated funds for the bereavement program. Many other groups also came]
on board, as did private donors, and all of these people helped to meet our challenge with funding.]

There were just so many challenges in developing something like that. We needed a location and we hunted and hunted and hunted for a proper location. For example, we thought maybe we could share [space with a church that was downsizing but various church policies made that not possible, or with the regional tertiary care children’s hospital but some understandable “territorial” issues arose. None of our leads for a potential location turned out to be suitable.]

Some people in the hospital… weren't so keen on our developing a hospice, particularly the oncology unit, because historically, [most children who die from an illness die from cancer.] As a result, oncology providers sometimes—not all of them—had considerable experience in dealing with death [and felt that there wasn’t a need for a hospice to provide palliative care. We decided that the best move would be to develop an independent, free-standing hospice rather than affiliating with another organization.] So, we turned out to be the first free-standing children's hospice in North America. Now, over time, the relationships with Children's Hospital have become warm and collaborative and work well.

There were challenges in finding appropriate people to fill our newly created staff [positions. Many applicants were interviewed. We expected that applicants with pediatric backgrounds would be the strongest candidates, but instead], it turned out applicants with a palliative care background, even if it was with adults, did much better because it was easier to teach them about children with their palliative care background than it was to teach pediatric clinicians about palliative care with their acute-care backgrounds. [So, our challenges involved] all kinds of things like that – [the kind of challenges that most people have when developing any new program.]

As time went on, our initial challenges got resolved and now, Canuck Place has recently opened a second children's hospice in British Columbia. It is located in a more rural part of B.C. There are now… six children's hospices across Canada now, based on the Canuck Place model. Even the first children’s hospice in California—George Mark Children's House [was based on the Canuck Place model. In 1999, I had returned to UCSF to become Chair of the Family Health Care Nursing Department and I served] on the advisory committee for George Mark Children's Hospice.
During my time in California, I also met a young intensive care physician from Texas, Marcia Levetown. She too was interested in pediatric palliative care. We worked together, along with others from around the US and with NHPCO [National Hospice and Palliative Care Organization] to establish ChiPPS, Children's [Project on Palliative/Hospice Services (now known as NHPCO’s Pediatric Advisory Council]. I'm sure Chuck told you about that. He still generously edits the Pediatric E-newsletter.

Bryan Sisk: From your perspective what really drove the development of pediatric palliative care becoming in the later 90s and early 2000s its own specialty? What was it that actually drove that development?

Betty Davies: I think there are several things. I think probably the most important thing is individual people who were committed to doing that and committed to the field. I think that most—what are they called—most developments, most movements, maybe. I guess developments is the best word. Most developments, whether that be some sort of building or a fund for a special project or for some kind of change, are spearheaded by individuals who are committed to an idea or a project. Without that kind of individual involvement of committed people, I don't think much ever happens. I think that was one factor.

Then, as those people found each other and developed professional liaisons and professional organizations, that provided more clout, so to speak, to catch people's attention and to bring a group together. I guess an example of that would be in Canada with the Canadian Hospice and Palliative Care Association.

Years ago, Stephen Liben [physician] and Barbara Sourkes [psychologist], who [was in Montreal at the time, and myself were interested in palliative care for children and we] tried to establish an interest group within CHPCA in pediatric palliative care. I don't even remember what year it was; mid to late 80s, maybe. We invited anyone that was at the annual conference to come and join our little group. [We made it known that this small group would be meeting, and we welcomed people to join us. Well, at the first meeting (Stephen and I were recently laughing about this)—there were three of us. That was it. The three of us. [laughs] But we continued to work together and, over time, more people came.]

Now, it's an active pediatric group, which has developed standards for pediatric palliative care, norms for pediatric practice, and other documents. It's an example of how just a few people started it and
then being stubborn enough, I guess, to keep going in the face of apparent lack of interest. It did attract interest and it grew. Now, it's become an official body. When the federal government, for example, wants some information about pediatric palliative care, that's the group they consult.

So, it's individuals and [individuals working together in professional liaisons.] I think another factor is the fact that children are [surviving life-threatening diagnoses, such as cancer, and also living longer with complex, chronic conditions – such as cystic fibrosis, metabolic and other disorders.] …Consequently, there's a long period of time where these children and their families need a lot of attention, a lot of supportive care. They are in need of palliative care when you define palliative care as [addressing the physical, psychosocial, emotional, and spiritual aspects of the child and family, from the time of diagnosis through bereavement for the child’s family.] It is helping people live while they're dying.

Another factor would be… the U.S. government report [edited by Marilyn Field and Richard Behrman]; it’s the 2003 Institute of Medicine report on [the needs of children when they die.]2 That evolved from a few people, including parents of children who have died, being interested, gathering up enough momentum to make a point to the Institute of Medicine, "This is something that needs to be studied. There's a lack, here." That report also served as an impetus for ongoing development of pediatric palliative care. I am very grateful for that [report because it served to verify and support the need for research about end of life issues.] In 1997, the National Institute for Nursing Research [led the NIH Initiative to coordinate research on end-of-life care–it was the funding body that actually “took the bulls by the horns” earlier than any other professional organization to allocate research funds for the study of end-of-life care. I was very fortunate to have moved to the US in 1999 and benefitted from this initiative and from the IOM report.]

When I moved to UCSF, I didn't actually know what NINR [National Institute of Nursing Research] stood for [laughs]. I had a lot to learn but I benefited because, as a faculty member at UCSF and as a permanent resident of the US, I qualified to apply for funding. That's where my funding came for a study on Chinese and Mexican families in pediatric palliative care and a study of fathers

---

in pediatric palliative care. Without that funding [and without colleagues who shared my passion for the field], I wouldn't have been able to do that research. That kind of funding has also supported many other people doing their research in the last 15 years. Then, the research findings get the ball rolling and provide more information and on we go, [building knowledge and ideas that aid the development of pediatric palliative care.]

**Bryan Sisk:** Thinking about—

**Betty Davies:** I'm sure there are other factors but that's what comes to mind.

**Bryan Sisk:** Thinking about Canuck Place, for a minute, was it a hospice more in line with the adult hospice where the children were coming there largely in the dying phases or is it more in line with Helen House, where it was a blend of end of life and respite care?

**Betty Davies:** It was a model based on Helen House so children come for respite and for end-of-life care.

**Bryan Sisk:** Along those lines, how much do you think the adult hospice movement and developments in that field influenced the development of pediatric hospice and palliative care?

**Betty Davies:** Well, I don't know, to tell you the truth [laughs]. I think adult hospice care, adult palliative care developed on its own. When St. Christopher's Hospice was founded, it was adults. Not much attention to children, except maybe the children of the patients who were there. When Bal Mount started up the palliative care unit—the first one in North America at Montreal General—his focus was on adults.

Most hospices were adult focused and though they shared the same philosophy about the need for palliative care and end-of-life care, they didn't really consider children. It was people like Sister Francis in the UK who [developed the first hospice for children, and Ida Martinson in the US who conducted her studies about homecare for dying children.] who spearheaded pediatric palliative care. The individuals who developed pediatric palliative care were pediatric people. They weren't adult-focused, they were children-focused.

I can say that in our development of Canuck Place, we focused on children but we also referred to literature that had to do with adult palliative care, but I think adult and pediatric palliative care followed two separate, but maybe parallel lines. In fact, there are
some articles written fairly recently about how there could be more of an exchange back and forth; a learning collaborative effort back and forth [between adult and child-centered palliative care]. For example, pediatric palliative care includes offering respite care to children with long-term, chronic, life-threatening conditions — in fact, the number of children with cancer in Canuck Place is a relatively small number compared to the number of children with neuromuscular disorders, for example. The adult world is now immersed in a state of shock over how to adapt our system to care for all the increasingly large numbers of people with pulmonary problems and cardiac problems who also are in need of palliative care. It's not just oncology patients anymore. [Perhaps lessons from the pediatric world could be applied to the adult world.] That way, we can learn together and maybe improve the whole of palliative care, even though we do it with different populations. I'd be interested to hear what other people have to say about that, because I'm sure I could learn something.

Bryan Sisk: Do you think there were any negative influences from the adult movement on the development of pediatric palliative care?

Betty Davies: I don't know. I think adult palliative care and adult hospice care are quite dissimilar, in some ways. In my experience, adult palliative care focuses a lot on medical care and symptom management. Nursing and social work and chaplaincy are secondary, even though there's a philosophy of collaborative teamwork. Whereas, I think in hospices, collaborative teamwork is stronger. I think that's one difference that has, potentially, a negative impact if you look at just at the palliative care part. If you look at the hospice part, it's a more positive impact. [In the US, the 6-month limit for hospice care for adults also does not fit for children and convincing funders of that difference has been a challenge. However, there are many differences in palliative care for adults and for children.]

Bryan Sisk: Given your body of work, I'm also interested in your thoughts on bereavement. Along this timeline you've been telling me about, when did concern and research about the bereavement of parents and the bereavement of siblings—when did that all come to the fore?

Betty Davies: Well, among the first articles about a family's responses to a dying child was by Binger, Ablin and colleagues³ in 1969. It was one of

the first articles that looked at the family's experiences with a
dying child [though in 1962, Olshansky coined the term "chronic
sorrow" as applied to parents of children with disabilities.] 
Looking at siblings of children with serious illness did not happen
until the late 70s, early 80s, [starting with Robin Kramer’s paper
on siblings of children with cancer.] …

Then, in the early 1980s, there were not only mine but about four
other dissertations that were published on sibling bereavement.
John Spinetta had also written a book on children with cancer and
in that, he mentions siblings.⁴

The impact on siblings didn't start until after the early 80s. It was
only after that, that articles came to be written about it. It
flourished for a while and actually it then died down a little bit.
Someone told me they think the reason for that is because families
are so much smaller. There aren't many siblings, anymore. I'm not
sure that's true, but it might be one explanation.

[01:07:40]

Bryan Sisk: Was bereavement considered part of the care of the dying child
and part of the hospice and palliative movement all along or was
that something that came on later?

Betty Davies: It was always part of pediatric hospice. Sister
Frances was explicit about [how hospice care includes supporting
families following the death of their child. In fact, Helen House
has a cold room for a child’s body to be kept for a period of time
so that families, including the siblings,] and children could come
and be supported in their grief, directly, right from the time of
death. At Canuck Place, [from the start, the bereavement program
was considered part of the hospice care program with]
bereavement counselors and bereavement groups for siblings of
children who were in the hospice and for parents. The emphasis on
grief and bereavement has been integral through the hospice
movement. Not so much to palliative care in hospitals.

[01:08:49]

Bryan Sisk: How so?

Betty Davies: I think, again, because of the focus on symptom management and
treatment. Once a person leaves the hospital, they're no longer a
patient in that hospital, family members are not considered patients

Pediatric Nursing, 5 (3),155-165.
⁴ The siblings of the child with cancer. In Spinetta, J & Spinetta, P. (Eds). Living with Childhood Cancer.
and it seems difficult to get people to feel the need to deal with even the grief that parents (or other family members) are feeling while their loved one is sick and dying. The focus is always mostly on the patient.

Trying to get family-centered care underway in hospitals has been challenging, but has improved in recent years. Some hospitals—particularly children's hospitals—have developed bereavement programs like B.C. Children's Hospital developed, albeit, a very simple bereavement program but it was better than anything that had existed before. That was to send sympathy cards to the families and contact them at six months and a year later just to see how they were doing and to acknowledge that their child had meant something to the staff who cared for him and that the staff was still concerned about the parents.

Bereavement care is not considered as part of acute care; therefore, it doesn't get much attention and it doesn't get much funding within organizations. Neither does the grief of healthcare professionals who work with dying patients all the time. That's a very important aspect that's totally ignored in most places.

[Bryan Sisk:]

Over your career, what have been the biggest changes just from when you started until now in the care provided to these kids?

Betty Davies: Well, let's see. [laughs] What would that be? From when I started? Well, from when I started, that would include the work of Eugenia Waechter, a nursing professor at UCSF from 1964 to her untimely death in 1982. She was the first to document that children younger than 10 actually experienced anxiety about the fact that they're dying. Myra Bluebond-Langner's work contributed to that finding as did John Spinetta's work. Piaget had posited that children do not have a mature concept of death until age nine; it was assumed, therefore, that seriously ill young children were unaware of what was happening to them. So, learning that young seriously ill children were anxious about their bodies and their future became a critical turning point in our understanding of seriously ill children.

[A second important change was in relation to location of care for children with cancer. When I started in nursing, these children

---

were admitted to general pediatric units in hospital for weeks at a time for their chemotherapy. If they lived far from the hospital, they were separated from their families for all that time. And, at that time, most children with leukemia died. Development of chemotherapy and radiation therapies resulted in the establishment of the first specialized cancer units for children in the mid-70s. As well, improved treatments came to mean that death from leukemia and many other cancers was no longer inevitable. When Ida Martinson’s work that showed that children’s chemotherapy could be administered at home or as outpatients without danger to the ill child, and with benefits for the child, parents, and siblings, that too triggered changes so that children did not have to spend extended periods of times in hospital. In the mid-1980s, Ann Goldman (Great Ormond Street Children’s Hospital in the UK) developed the first combined hospital and homecare program for children with cancer. The first pediatric palliative care unit was developed in 1986 in Canada at Toronto Sick Children’s Hospital and followed shortly thereafter by a unit at Montreal Children’s Hospital.

[With medical and technological advancements, the development of children’s hospices grew and created another location of care for children and their families. From the start, children’s hospice focused on children with life-threatening complex, chronic conditions. During my early clinical years, most children with such conditions died at birth or shortly afterwards; today, such children can live for months and even years. Sister Frances Dominica, the nurse and Anglican Sister, created Helen House in 1982 with the mission to provide respite as well as end-of-life care and bereavement follow-up for families of these children.8 Situated in Oxford, England, Helen House was the world’s first free-standing children’s hospice and has served as the model for other hospices in the UK and throughout the world.]

A third change that I have witnessed is the development of professional international organizations, such as Children's Hospice International, and more recently, the ICPCN (International Children's Palliative Care Network). [Now, pediatric palliative care conferences are hosted throughout the world.]

Fourth, I witnessed the development of the first published articles and textbooks on palliative care. The Oxford Textbook of Medicine

---

published in 1993⁹, edited by Neil MacDonald and others, was the first textbook on palliative care in medicine. In it was a section that I edited on pediatric palliative care. That was the first time that anything had been published specifically on pediatric palliative care. Of course, numerous other publications have been written by many people since then. Other developments have occurred…

[01:14:37]

Bryan Sisk: Not yet.

Betty Davies: Papadatou. Danai (a psychologist) and her father (a pediatrician) hosted the first conference that brought together people interested in death, dying, and bereavement and children. It was an international conference held in Athens. Participants came from many parts of the world; it was the first time that educators, practitioners, and researchers came together to actually talk about their work, as a group. She and her dad published a book based on the work that was presented at that meeting.¹⁰ [Danai is the founder of the first palliative home care and bereavement program in Athens, Greece, serving as a model for much of Europe.]

What else? Fifth would be the development of bereavement programs for children. When developing the bereavement program for Canuck Place, I conducted a survey of bereavement programs for children in the US, Canada, AU and the UK. At that point, there were only a handful, and now there are literally hundreds, many of which are modelled on the Dougy Center in Portland, Oregon. That program was actually started by another nurse, Beverly Chappell. I always like to point out that many, if not most, hospices and palliative care efforts in pediatrics—even in adults—started with nurses [laugh]. Donna Schuurman has been the executive director and CEO for many years and recently stepped down now to assume the role of Director of Advocacy and Training. Donna has been involved in childhood bereavement for many years, so she might be someone else you're interested in talking to.

Another change has been the expansion of palliative care focusing on children with cancer to children with a wide variety of life-threatening illnesses. Here's another person you might want to interview: Rana Limbo in La Crosse, Wisconsin. She developed Resolve Through Sharing which is a palliative care program for

---


perinatal death. Today, NICUs [Neonatal intensive care unit] have a much greater focus on palliative care. It's still in development.

What else? Well, the development of documents outlining standards and principles of care. One example, starting in the early 90s is the Association for Children with Life Threatening or Terminal Conditions and their Families (ACT), now known as Together for Short Lives, based in the UK, aims to achieve better quality of life and care for all life-limited children and their families, accomplished in part by the publication of numerous resource documents. They continue to develop updated versions every so often. I'm sure you have that or you're aware of that?


Betty Davies: What else? Now, internationally, there are pediatric palliative care programs and hospices in Germany and there's one in Portugal and there's one in South America. New ones are in development in many locations. Palliative care has more of an international flavor than it did. Anyway, I think that's it.

I wrote a paper—a chapter in a book—where I described the development of pediatric palliative care. It's called “Palliative care for children.” It's in a book called Death, Dying, and Bereavement: Contemporary Perspectives, Institutions, and Practices11. I could send you that chapter. I think it might outline some of the things I've talked about now. I think those are some of them, anyway—there have been so many changes. [laughs]

[01:18:37] Bryan Sisk: Just a couple more questions to wrap up. What do you think are the biggest challenges facing the field, right now?

Betty Davies: Biggest challenges now. Let me think. I did think about this, but then that was a while ago. Oh, I know. I think I wrote about that in this chapter, actually. I think one of the challenges is the uncertainty now of many unfamiliar conditions with unpredictable trajectories that only compound uncertainty about how children are going to respond to any kind of treatment because, for many children, even the diagnoses are very rare and hard to identify.

There aren't, for some diagnoses, large enough groups of children to actually develop standard procedures for treatment. I think that all of that together—that uncertainty— affects how people make decisions. It emphasizes, I think, what I call a “cure versus

palliative” thinking. That is, "Let's keep searching. There's got to be a way to cure this child; to deal with this disease. There's gotta be a way." I think that determination and curiosity sometimes inhibits both providers and parents from acknowledging that maybe there's not a way, yet, at this point in time.

So, let’s talk about this a little bit differently: Instead of thinking "Okay, what other things can we try?" focusing instead on—"So, what might we like to try and what do we not want to try? Is it time to focus on comfort, on recognizing that this child will not survive?" I think that first kind of thinking can influence a delay in referring children for palliative care or hospice care. It’s important to recognize that the fact is, with this condition, most children die, so let's look at it a little bit differently by acknowledging that and figuring out what's best for this child, for these parents, at this time. I think that's one of the things that—one of the areas where, for example, the relationship between Children's Hospital and Canuck Place has greatly improved, in that our physician, Hal Siden, is called in now much earlier and more frequently for children with—oh, what might be called weird (mysterious) diagnoses—to bring in that palliative perspective and how to deal with the uncertainty of that child’s situation.

I think another challenge that I see in many, many areas of healthcare and very many places, is the whole focus on “How can we be more efficient?” I think the efficiency model guides most healthcare institutions and it jeopardizes the kind of care that is required for optimal palliative care. That is, person-centered, family-centered care – which takes time. It also takes a certain—requires healthcare providers with a certain—a different kind of perspective than, maybe, the administrative world sees as important with their desire for efficiency in meeting specified, measurable goals.

Another challenge I think is important is how to provide care that is transitioning care from pediatric to adult programs. When a child has to move from pediatrics for example, at 18 or 19, which is the upper limit for age in pediatric services. Although some kids stay longer, depending on their situation, but most of them at 18 transfer into the acute-care, adult system. That's really, really difficult. Instead of being a seamless kind of transition, it becomes one with all kinds of bumps and bruises and the people who get knocked up the most are the kids themselves.

I also think that there needs to be more attention to grief and loss of children and parents and staff throughout the whole system. We
tend not to acknowledge the person who is the healthcare provider and how that influences how they do their work, what they do, how they relate to children and parents, *et cetera*. There's still a great need for putting more emphasis on incorporating bereavement care into what we do. Stephen Liben—I don't remember if you said you talked to him or you said you are scheduled to.

[Bryan Sisk]
Mm-hmm.

[Betty Davies]
He and Danai have written an article about the challenges in the future of pediatric palliative care\(^\text{12}\) that you'll find it useful if you don't have it already. They'll tell you about it when you talk to them *[laughs]*.

[01:24:39]

[Bryan Sisk]
What do you think are the strongest areas in the field right now?

[Betty Davies]
The strongest areas. I think the growth, which represents the realization that there are children who live with life-threatening conditions that are extremely, extremely challenging for their parents. I think people are becoming more aware of that and, therefore, are more willing to offer support by donating money or volunteering or whatever to the field. I think the amount of research that's being done is a strength. An increasing number of professionals are interested in the field, whereas before there were very few *[laughs]*. Those are just a few that I can think of.

[01:25:47]

[Bryan Sisk]
Lastly, I'd love for you to dream aloud. If budget and politics and uncertainty—all of those things we were talking about. If none of those were obstacles, what would you ideally want care for these children to look like in another 10 years?

[Betty Davies]
Well, I'd like it to address the aspect of seamlessness so that there is a flow of communication. A back and forth—not just one way—but back and forth between and among children's hospices and adult hospices and adult care so that as children grow and graduate, so to speak, to the adult system, it's much more friendly and effective in providing optimal care to those children and their families.

Part of that seamless care includes the whole aspect of bereavement so that bereavement follow-up occurs. A service to help children and parents cope with loss during children's time in the hospice, but also… continues through to the death and beyond that. Whether that is offered by the hospices or the hospitals can be

open for debate, but it needs to be somewhere. Maybe bereavement care could be incorporated into a public health system or a community system.

At the moment, parents whose child dies from trauma or a non-hospice situation seldom receive any sort of support for their grief. [Grief support is not typically a focus] in hospital settings. I would like to see—generally, my pie in the sky hope would be that the general society would be more willing and comfortable in talking about death and in realizing that we are all going to die, so let's accept that and incorporate that into the transitions of our lives.

However, the fear of death is a basic human fear that we probably can't overcome, but certainly, we can learn to live better with it. But change is occurring… it used to be that no one ever talked about death, really. Now, [I hear people talking about death. I think it may be frequently within the context of murder mysteries, or war stories, or science fiction on TV. We also hear and see more news stories and photographs from warzones, from riots around the world] - all of which have to do with violence and death. [But if we could respond to such things by engaging in conversations about the uncertainties of life and the certainties of illness, loss and death, then maybe we could learn to live our lives with deeper meaning, practicing the principles of palliative and hospice care as we go about our daily lives.] …

**Bryan Sisk:** What a wonderful dream. Maybe it won't be a dream, someday.

**Betty Davies:** [laughs] Oh, I hope it won’t be just a dream. But I do think that's a contribution that people in palliative care, in hospice care can make. We can be more willing to talk to people about death, about grief. We can talk about our work. I'm sure you've had this experience or if you haven't, you will. If I'm sitting on an air—I don't talk to people on airplanes, anymore. Mostly, because I get airsick if I turn my head sideways [laughs].

[01:30:23]

**Bryan Sisk:** [laughs]

**Betty Davies:** I just find that it takes all my energy. This is what used to happen. People would say things like, "Oh, so where are you going? Do you live in Montreal?" "No. I'm going to a conference." "Oh, really? What kind?" "Well, it's an international conference." "Oh, really? That sounds impressive. What's it about?" "Well, it's actually about palliative care." "Palliative care? What's that?" Well, so it's an opportunity to explain it, but sometimes when I
Bryan Sisk: "You mean, you work with children who die? Oh, you must be really special." [laughs]

Betty Davies: "No. No. It doesn't have to do with being special. It has to do with..." It's an opportunity to teach people and even if you just do it with one person at a time, it makes a difference. If I get on a plane and I'm really tired or I really have work to do, then I don't talk much because three hours later, I'm still talking [laughs].

Bryan Sisk: [laughs]

Betty Davies: By that time, I'm really motion sick. So [laughs] anyway, but I do think there's a societal contribution to the work that we do.

Bryan Sisk: Well, this has been really phenomenal. Those are all the questions I had, but is there anything else about this history that you think I have missed or that I should really give more thought to?

Betty Davies: I don't know [laughs]. I'll send you my chapter and I'll review it, too, and see if there's anything there. Oh, I know one thing I talk about in the chapter. When you talk about the difference between adult and pediatric or whether there's an influence there, I think there are some very significant differences in pediatric versus adult palliative care and hospice care because we're dealing with children.

That's an important thing. People who work with children have to be very aware of child development. Even some people in pediatrics are not enough aware of that, in my opinion. You have to understand how children grow and develop and what they need and what they don't need and when and where and how. We don't need to do that so much with adults. They have their own developmental stages, but by the time they get to be adults, they can figure out how to go through those, by themselves [laughs]. All kinds of books are written about and for adults, but children are dependent on the adults who look after them. As pediatric people, we have an obligation, I think, to really know about what children need at various stages of development.

I think the other difference is that it's particularly sad when it's a younger person who is dying, and is particularly hard for a young mom or dad. When people who are older die, it's very sad and difficult for people, but it's considered normal. It's expected that, at some point, people will die when they're old but children—the
death of a child is never considered normal and it's totally out of sync with how the world's supposed to operate. That adds an extra layer of challenge, I think, for people working in pediatrics.

Oh, the other thing that comes to mind is that we've cared for children in the hospice where, in some families, there's more than one child with the condition because it's familial. Maybe it's a genetic condition and it affects more than one child. Very seldom does that happen with adults. I mean, more than one person in a family may have heart disease, but [laughs] it doesn't have the same impact as two children who have the same neurological or muscular disorder.

[01:34:48]

Bryan Sisk: Absolutely. Well, thank you again. I really appreciate all of your time.

Betty Davies: Well, you're welcome.

[End of Audio]