Charles Corr Oral History.

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

Recommended Citation
https://digitalcommons.wustl.edu/ped_pal_oral_hist/5

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. Charles “Chuck” Corr, PhD., M.A., invested over 40 years into publications of research on pediatric and adolescent death, dying, and bereavement. He has held numerous leadership roles including Professor Emeritus in the department of Philosophical Studies at Southern Illinois University Edwardsville, former chairperson of the International Work Group on Death, Dying, and Bereavement, and membership of the executive committee of the National Donor Family Council. He has been recognized with numerous awards and authored and co-authored over 40 books, 130 journals and book chapters, 110 newsletter articles, and over 70 electronic publications. While now retired, Dr. Corr continues to edit and co-produces NHPCO’s quarterly Pediatric E-Journal (formerly ChiPPS E-Journal).

Interview Abstract
Dr. Charles Corr begins by explaining how his career in pediatric death, dying, and bereavement began “almost accidently” as he stepped into the instructor role of a death and dying course in the mid-1970s. After that experience, Dr. Corr focused more on teaching classes on children and dying and gathering experiences alongside clinicians in the pediatric palliative field. He explains that as a trained academic writer, he was grateful when pediatric clinicians, patients, and families allowed him to share in their experiences and write them up. Dr. Corr goes on to describe the changes he’s experienced in the field that have removed some of the barriers he experienced in his early career, as well as the strengths of the multidimensional care he has experienced in the field. Dr. Corr ends by identifying patient transitions and seamless care models for patients, especially those that age out of pediatric care, as next frontier for this field.
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>ChiPPS</td>
<td>Children's Project on Palliative/Hospice Service</td>
</tr>
<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
</tr>
<tr>
<td>NHPCO</td>
<td>National Hospice and Palliative Care Organization</td>
</tr>
<tr>
<td>SIUE</td>
<td>Southern Illinois University Edwardsville</td>
</tr>
<tr>
<td>SLU</td>
<td>Saint Louis University</td>
</tr>
</tbody>
</table>
# Interview Roadmap

## Beginnings

- Personal career influences
- Colleagues, mentors, mentees, and other influential figures

## Pediatric death, dying, and bereavement

- Evolution of pediatric palliative care and bioethics movement
- Death, Dying, and Bereavement courses
- Publications
- International work study
- Reframing healthcare for hope and multidimensions of care
- Challenges
- Strengths
- The future

## Relationship to adult hospice and palliative care

- Patient and family-oriented care
- Parallel journeys
## Related Works and Mentions

<table>
<thead>
<tr>
<th>Mention</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>As I Lay Dying</em></td>
<td>8</td>
</tr>
<tr>
<td>Carter, Brian</td>
<td>12</td>
</tr>
<tr>
<td>Faulkner, William</td>
<td>8</td>
</tr>
<tr>
<td>Feudtner, Chris</td>
<td>14</td>
</tr>
<tr>
<td><em>Hospice Approaches to Pediatric Care</em></td>
<td>2, 3</td>
</tr>
<tr>
<td>Kastenbaum, Robert &quot;Bob&quot;</td>
<td>1</td>
</tr>
<tr>
<td>Klass, Dennis &quot;Danny&quot;</td>
<td>9</td>
</tr>
<tr>
<td>Liben, Stephen</td>
<td>12</td>
</tr>
<tr>
<td>Martinson, Ida</td>
<td>2, 3</td>
</tr>
<tr>
<td>Mount, Balfour &quot;Bal&quot;</td>
<td>14</td>
</tr>
<tr>
<td>Parkes, Colin Murray</td>
<td>10</td>
</tr>
<tr>
<td>Saunders, Dame Cicely</td>
<td>6, 10</td>
</tr>
<tr>
<td>Siden, Hal</td>
<td>12</td>
</tr>
<tr>
<td>Torklidson, Christy</td>
<td>12</td>
</tr>
<tr>
<td>Wass, Hannahlore</td>
<td>2</td>
</tr>
<tr>
<td>Wilkes, Eric</td>
<td>8</td>
</tr>
</tbody>
</table>

**Edited for grammar and content by Dr. Davies.**
Bryan Sisk: Today is May 3, 2019 and I am Bryan Sisk. I'm in St. Louis, Missouri. I'm interviewing Dr. Charles Corr over the telephone for the Pediatric Palliative Care Oral History Project and Dr. Corr is in Florida currently. Dr. Corr, thank you for joining me today. To get us started, could you just tell me what first turned your mind toward pediatric palliative care and death in children as a focus for your career?

Charles Corr: Yes, I began by stumbling into the teaching of a death and dying course. My university created a requirement for every student at the junior level to take an interdisciplinary course. We didn't have such courses. So a colleague in psychology and I proposed a death and dying course. I don't really know why we did that. As you look back now, you think we were woefully unqualified to teach such a course. One of the great writers in this field of thanatology, Bob Kastenbaum said one time, "The first time I stepped into a course on death and dying, I was the instructor." Well, that's true for me, too.

This was in the mid-70s. There were no formal ways to prepare yourself for doing that kind of teaching. We did a lot of things. We team taught. We listened to guest speakers. We read widely, as widely as we could. We tried to get connected to new bereavement support groups and new hospice programs when they began to arise. In other words, we did everything we could to improve our competencies. That's the background is a death and dying course.

What we discovered in the teaching of that course is it was very popular. It was very stimulating both for students and for the instructors. In such a course, you can probably only allocate a couple of hours to issues related to children and adolescents and maybe also a couple of hours to issues at that time, related to hospice care. I got more and more interested in those kinds of issues. What was the literature for kids about death and dying and bereavement? What were programs?

Eventually, I proposed a second course, a course on children and death and that course actually got approved without much objection. I went around and solicited support from all the relevant departments, psychology and nursing and social work. We had a good reputation for the death and dying course. It was very popular and the new children and death course attracted pretty large audiences for such a specialized topic. In a way, it is the teaching. Probably most of the people that you will interview will be clinicians. I'm not a clinician. I'm an academic and I came to it...
from a classic background of teaching in the broad field of death, dying and bereavement. Do you wanna stop there for a minute or do you have any questions? Is that clear?

Bryan Sisk: One question I had is, I'm familiar with a lot of the philosophy that was addressing death and dying generally in an adult and suffering in the adult world, but where did you turn to try to find specific insights into children back in the, I guess it was the late 70s?

Charles Corr: Yes, it was. Well, after teaching for a while, I connected with a colleague. Her name was Hannahlore Wass. She was a German native who came to the United States and was teaching at the University of Florida. She was interested in issues related to children and so was I and so, we said to ourselves, "Could we propose a book on children and death?" We did that and at the same time, my wife who was a nurse was teaching in a community college and I proposed a book on hospice care, hospice principles and practice. I guess we were people who wanted to write, who wanted to edit, and we had a flash one [laughs] night.

I went to a conference and I listened to Ida Martinson. As you may know, she started a program on home care for dying children in Minnesota and I came home and said to Donna, "We have a book on hospice principles that's in the work. We have a book on children and death. That's in the work and there's nothing crossing over between them. Maybe we could do a book on hospice principles in pediatric care," and so, we proposed such a book and our publisher accepted it and we rounded up a lot of people who were doin' various things at that time, but they were all pretty much operating in isolation. There were people doin' what they called—I don't know.

Let me see what they called—there was stuff on children and grief. There was stuff on parental bereavement. There were people doin' home care. There were people doin' respite care. Helen House in England was the first hospice facility. They would say, "A respite facility," and there were people in—I forget where they were located, but in Denver I think. They were doin' neonatal, what they called, "Neonatal hospice care." We asked each of them would they write a chapter for the book we had in mind and we got a lot of cooperation and eventually, the book got published. I think that was in the early 90s, maybe '93, '94.

Bryan Sisk: This is the Hospice Approaches to palliative care or pediatric care?¹

Charles Corr: Hospice Approaches to Pediatric Care¹, yeah.

Bryan Sisk: I've got it in front of me. It was 1985.

Charles Corr: Oh [laughs] well, good for you then [laughs].

Bryan Sisk: [laughs].

Charles Corr: You're more accurate on your data than I am. Yeah, I have it in front of me, too, and I didn't bother to look at the—yes, right.

Bryan Sisk: When did—

Charles Corr: Go.

00:07:12

Bryan Sisk: When did this work going into that book?

Charles Corr: Oh, it probably would've started a year or two years before. It usually takes a good year to round up people, to give them time to write, to invite them, to negotiate with them about what they're gonna write about, to give the time to write and then to put all that together and send it into the publisher. Then the publisher does their machinations, copyediting and all that kind of stuff. Usually, we think a year or maybe two years, a year and a half to produce a book like this.

00:07:51

Bryan Sisk: Before this, back when you were starting your death and dying course, it sounds like there were similar minds around, but there wasn't necessarily a community of these similar minds. How did that develop over time?

Charles Corr: Yeah, there was no real community. You're right. There were just people doin' as they used to say in the Vietnam War, "flourishing where you are. Grow where you are." And so, some people in neonatal unit were thinking about this. Some people, Ida Martinson's program in Minnesota was largely a nurse-driven program. There was a facility in New York City, really a kind of long-term care facility for children and they were trying to do somethin'. There were a lot of people on their own trying to make initiatives for better care as they understood it for children and family members, siblings and parents and we just tapped into that I think and we said, "Let's see if we can make a book here."

00:09:07

Bryan Sisk: When did that, all those disparate people that were flourishing in their own places, when did all of them start to come together into
I guess you would say that in the way I've described it and you've captured it again by saying that that's all pretty much in the early 80s.

But I think the real impetus was in the late 90s when people persuaded the National Hospice Organization to create what they call ChiPPS, originally it was Children's International Project on Palliative and Hospice Care. That was oh, '98. They got together maybe about 30 people. I don't know the exact count, people who were interested in pediatric care and relating that to palliative to hospice or palliative care. There was a two-day meeting in Dallas, Texas and I was invited to that although most of the people there were clinicians and I think it was the impetus that the NHPCO [National Hospice and Palliative Care Organization] gave to the ChiPPS project that really pushed things forward.

They tried. They created a bunch of workgroups. They tried to create what they called a Compendium of Pediatric Palliative Care\(^2\), a kind of large book that would bring together all the documents that were available in that book. One of the groups wrote a white paper saying we need more attention to pediatric palliative care. Eventually, three or four years later, they developed an educational curriculum for pediatric palliative care. What became most connected to me was an electronic newsletter, which started right around 2003 I think, and what I learned is that the kinds of contributions I could most usefully make were not in direct provision of care.

They probably also weren't—there was a leadership council for ChiPPS and most of those people their work was in pediatric palliative or hospice care, but mine wasn't. Mine was writing and editing and so, eventually it seemed to me to find a natural place for me was serving as an editor for the ChiPPS newsletter. It was originally called a newsletter and then it became what they call an "E-journal," and I think they're now gonna' call it a pediatric journal, pediatric care journal. They've just changed names in

NHPCO. What I like about that is it's a quarterly journal. It's free. It focuses on different subjects related to pediatric palliative or hospice care and what I can do for them I think is the work that an editor would do. I don't see myself as someone who could deliver care to children and families, but I do see myself as someone who could be a good editor and an organizer of material and that's gone on now for, well we're talkin' about, I don't know, 15 years or so.

I didn't really anticipate all of this [laughs]. I just wanted originally to be a better teacher. I wanted to be better qualified to teach students at the college level about subjects related to death, dying, and bereavement originally, but then secondly to children and their families who were encountering issues related to death, dying and bereavement and then another thing that came to my attention is adolescents. Somehow, adolescents were being treated as just like children, big children or as young adults, but not as a population group in its own right and so, we went on to a book on adolescents and death.

Actually, I think we've edited with the different partners three or four books now, [laughs] most of which are out of print now up to 2010 or so, a little less than 10 years ago. We had a very active publishing agenda for quite a long time. I think maybe I always wanted to write. I always wanted to edit. I had good models when I was a graduate student. They were writing and editing and teaching and I wanted to do that too. And I think those are the qualifications that I have to contribute to this field.

Bryan Sisk: You got into this field almost on a fluke and then you stayed in it initially because you wanted to become a better teacher. What was it that drove you to really invest in it over the subsequent 30, 40 years?

Charles Corr: [laughs] yeah, it's a good question. There was always stimulation there. There was always things to learn, always things to try to teach, to try to communicate to people. I think what a good teacher does is listen to folks who are on the frontline, for example, listen to people who are delivering hospice care. I led work-study trips to a British hospice, an adult hospice for eight or nine years in the summer for two weeks. I watched what those people were doin', the kind of care they were giving and then I came back to the United States and I tried to teach people about that kind of care and some people would say, "Oh, you can't do it. You can't deal pain. You can't deal with the kind of things that people face when they're near the end of their life. What can you do for bereaved folks?"
Well, you can learn a lot by talking to the people who are having those experiences or professionally caring for some of them.

Really, I guess I would say this another way. A lot of people in the last 30 or 40 years have allowed me to come into their lives at very difficult times, time when they were dying, when one of their family members was dying, when they had a child who was dying or seriously ill or professionals who were caring for all of those kinds of people. They allowed me to learn about their experiences or their work and then try to communicate that and my way of communicating is to edit books or to write articles. When we did the book on hospice approaches to pediatric care, we wrote a couple of articles and got them published in various journals, hospice journals or I think we even had one in *Pediatrics* once and people wondered, "who were these folks writin' about [laughs] this subject?" [laughs]

A fair question, but there was a lot of in the early years, there was a lot of misunderstanding, a lot of confusion, a lot of—there were people who didn't know what the hot-spice movement was. There were people who were nervous about coming in at the end-of-life. There was a short editorial in I think in *JAMA* saying, "Do we wanna transfer patients to these places of little hope?" I thought wow, such a misunderstanding there. You gotta' think about different kinds of hope. You have to think about different kinds of care. There were people who talked about, well, when we come to the end of active treatment, but if you talk about active treatment and say, "We're comin' to the end," then what do you have left passive treatment? That's just nonsense. What we tried to make clear to people is, there's a different kinda focus here and there is as Cicely Saunders would've said, "There is intensive care. It's just directed at different goals." I don't know if I'm answering your questions. If your questions.

[00:19:00]

*Bryan Sisk:* When you were starting out your children and death course—

*Charles Corr:* Yes.

[00:19:10]

*Bryan Sisk:* - thinking more so from your humanities background, were there philosophers and ethicists who were thinking or writing about childhood death at that time?

*Charles Corr:* I don't think there were a lot of people from that kind of background. I think my professional background is largely divorced from this. I was not a person who was particularly interested in ethical issues. I was trained as a historian in
philosophy. I think one of my colleagues once said, "Maybe what you guys can contribute is focusing on conceptual clarity. You can ask people to think about concepts here like different modes of care. How does palliative care interact with cure-oriented care, for example." My general impression of pediatricians is that they were always focused on family, family units. That is to say, they didn't just focus on a sick child. Whereas a lot of adult-care providers seemed maybe only to focus on that one person. I thought pediatricians or pediatric nurses, social workers, chaplains had a great start in thinking about family units and how children who are dealing with a life-threatening or a life-limiting condition were fixed in a family unit. What about the other children in that family unit? Or what about the parents who get separated and come to really fine pediatric hospitals like those that are in St. Louis? We lived in St. Louis for a long time. So, I know a little bit about it.

[B00:21:08]  
Bryan Sisk: Yeah, I saw your graduate degrees were from SLU I think, right?  

Charles Corr: That's right, yes and then I taught at Edwardsville.

Bryan Sisk: Okay, yeah.  

Charles Corr: Well, I did wanted to teach there for a year so that I could finish my dissertation. And 34 years later, I retired from [laughs] SIUE.

[B00:21:29]  
Bryan Sisk: Funny how things work.  

Charles Corr: Yes and you know, I think I have to say that I had a very open-minded department. They allowed people like me to teach courses in subjects that were not typical of philosophy departments and I wasn't the only one. Some of my colleagues taught other subjects that they were interested in that go beyond critical thinking and introduction to philosophy and things of that sort. Really, I benefited from a broadminded department at Edwardsville and as I've already said lots of people who let me into their lives and lots of professionals. I hope it was because I didn't threaten any of them professionally. I wasn't another doctor. I wasn't another nurse or a social worker or whatever. I was a student. I wanted to be a student and to learn from and pediatric care was just burgeoning, I think. It was just lucky. To try to walk into this field now is a major job I think, but lots of people let me in.

[B00:22:49]  
Bryan Sisk: You talked about how grateful you are for the people letting you in at those times in your lives. On the flipside of that, did you ever sense from resistance from clinicians because you weren't a clinician and you were writing about these things?
Charles Corr: Oh, yes [laughs] from academicians and from clinicians. From academicians when the dying course was proposed some of the colleagues on the curriculum committee said, "You know the only people who are qualified to teach a course about death and dying are priests, ministers or rabbis. Of course, we wouldn't wanna' have priests, ministers or rabbis on the faculty of a public university," Really silly. One of them went so far as to say there's no such thing as dying and the chair of the English department said, “Well, then Faulkner is gonna' have to re-title his book, As I Lay Dying [laughs]."

[00:23:43]

Bryan Sisk: [laughs].

Charles Corr: I think we just sneaked the death and dying course through, but the children and death course was much easier because we had a history. We had a population on campus that was interested. We were able to allow other people off campus to attract mid-career professionals who wanted to learn more about these areas or who wanted to go on a hospice work-study trip. Now, you asked me what about clinicians' resistance. Yep, I wrote originally to St. Christopher's Hospice in England and said, "Could I come for a summer as a volunteer?" and I got turned down pretty quickly. I think that was because I was not a clinician myself and I was an American. I don't mean that they never took in Americans, but this was very early.

I wrote almost at the same time to St. Luke's in Sheffield, and they took us in and I think there was a lot of courage in that. They had a great medical director, Eric Wilkes, who was a wonderful physician and a wonderful leader and I think it was courageous to take in—I was probably about 40 or something like that at the time. I was an academician. I had a nurse wife. I had three children. We wanted to all come for the summer and they let us come. My children attended British schools. My wife and I volunteered at St. Luke's and the British were very careful of us as they would be with anyone, especially anyone who's gonna' have direct contact with patients and families, until they were sure that we were okay, we could be relied on. Then they increasingly broadened what we could be involved in. So, yeah, there was resistance, sure, not an awful lot, but some.

[00:25:59]

Bryan Sisk: What years were that?

Charles Corr: Ooh, I think I led those work-study trips from the late 70s to the late 80s. I'd have to check the dates to be accurate with that.
When thinkin' about all of your experiences as a volunteer and as an observer of what's going on without being that clinician, what did you view as the biggest challenges in caring for these children that were suffering and dying at that time?

Well, I first volunteered at an adult hospice. That was maybe a little easier. Every time I would meet someone, I would say, "I'm an American [laughs] out of Yorkshire." My accent stood out pretty clearly and people called me Chuck and Charlie would've gone over even more easily. The medical director was Professor Wilkes. He was a physician, but he was also a professor at the medical school and so, they called him Prof. Wilkes and they called me Prof. Corr, which I liked a lot.

In terms of getting direct contact with children, I don't know that I've had that much as I did with an adult hospice care in St. Louis. As you may know, that kind of care began at Lutheran Hospital in south St. Louis and really, I think in some ways, it was an effort to fill empty beds and folks at Washington U. were happy to transfer patients to Lutheran Hospital. I betcha' they wouldn't do that anymore. [laughs] I betcha' there are thriving palliative care and hospice programs linked to your medical school.

Correct. [laughs]

Right. In terms of children, I think my involvement has been very broad but shallow. What I mean by that is I haven't worked intensively with ill children or their families. I did become an advisor to a Compassionate Friends group in Alton. As you know, Compassionate Friends are bereavement support groups for parents and other family members and visiting those groups was very helpful to me. It taught me a lot I think about it. Denny Klass did much the same in St. Louis with a Compassionate Friends group and he developed a book out of that. I don't know. I think I'm drifting. I should stop now and come back to your question.

I'm also thinking about what suffering means for these children with really serious illnesses. From some research I have done, it seems like the people thought about different components of suffering. They thought about psychological angst. They thought about pain eventually and they thought about these types of things, but it seems like that didn't necessarily pull into a holistic concept of suffering until later on. Do you have experience with that or thoughts about that?
Charles Corr: Yeah, that would be my impression, too, that people focused on pieces of things and pieces of hope, pieces of care, pieces of suffering. It's fine for example, if we can do great work to reduce physical pain, trying to explain to students that reducing pain from agony to ache is a big achievement even if you're still thinking, you're still a lot better off than you were when you were just agonized with pain. [coughs] I think also that relates to hope. What kind of hope can you have for family members?

[Extraneous conversation 00:30:14 – 00:30:27]

[00:30:28]
Bryan Sisk: When do you think the holistic view started to come into the fold?

Charles Corr: Oh, I think it's part of the whole hospice philosophy I think. Someone said one time that hospice is a philosophy not a facility. And we still find students—I've been teaching an online until the last year for a Canadian university and we still find people who say, "Oh, I thought it was a place." But a lot of hospice care especially in the U.S. as you know, is delivered in homes. Yes, there are hospice facilities. Yes, there are units in large medical centers. I think it was Cicely Saunders who taught us that we have to think about physical, psychological, social and spiritual. That was very meaningful to me. She was always a person who emphasized the spiritual dimension of care.

For me, that was instructive that we weren't trying to care for just pain or nausea or whatever a physical symptom might be. Of course, we were trying to do that, but we were also trying to think about other dimensions of care. Colin Parkes once did a study of people and he found that there were a lot of patients at St. Christopher's who wanted to go home. They knew that they might not get as good care at home as they would in St. Christopher's where there trained nurses and other specialists who could watch over them 24 hours a day, but being home was really important to them, being in a place with their own people eating their own foods. Lots of things matter and I think careful clinicians learn to listen and have families tell them what's most important to them.

[00:32:49]
Bryan Sisk: We've talked about your career and a little bit about how it developed. With your kind, it seems like almost a niche career where you couldn't have planned it out the way it happened if you had tried, but everything fell into the way it ended up being.

Charles Corr: Yeah, that's absolutely true. I was trained to teach the history of philosophy, what we call modern philosophy. I was very academic,
very conceptual, very—and I never imagined being a caregiver other than in so far as a teacher is someone who cares for his or her students, but I never imagined being a caregiver in the sense of a clinician. My wife is a nurse. She used [laughs] to ask me, "What am I writing about here? What does this paragraph mean and how are nurses gonna' understand that?" I learned a lot from her and I learned that she knew—she's a wonderful bedside nurse.

I think she would've stayed at St. Luke's for the rest of her life she so admired the bedside care there, but we had three children [laughs] and we had a home in St. Louis. So, we needed to come back. Yeah, this is not a career I planned. It is a career, which began almost accidentally. It is a career that probably couldn't have begun now in the same way. It just happened that that was an early time when lots of initiatives were goin' on and that means that a lot of other things weren't gettin' done. My guess is that I'm not a model in terms of a career, but I hope I've been able to contribute in useful ways.

What do you think were the biggest challenges you faced in your career, traveling along this line between the humanities and between the clinical care of children?

That's a good question. The biggest challenges, access for one. Would people allow someone like me to come into their support group, their bereavement support group or come into the brand new hospice program at Lutheran Medical Center in St. Louis? I once said to a parent, a father, in a bereavement support group in Belleville. He said, "We'd like you to come and talk to our group about"—I think it was about gettin' through the holidays or something like that and I said, "You know, Joe, I'm a little nervous about that because I'm not a bereaved parent and so for me to be telling people how they should live out their bereavement."

He said, "That's okay. We don't want you to be a bereaved parent. The entry price is too high." And I thought, "You're absolutely right, guy." What I can tell people about is what I've read, what I've learned from the literature, what other people have told me. I can be a communicator I think and I think that’s what good teaching is about. But yeah, so challenges. We didn't encounter a lot of challenges in terms of publishing books. There was a lot of interest in these subjects. There were a lot of people who had come to points in their career where they had something to say. They wanted to tell people about the care they were delivering. Maybe it was home care to dying children. Maybe it was, well, for the
ChiPPS newsletter, we've just edited an issue now that will go into distribution sometime this month.

There are people doing aquatic therapy. There are end-of-life doulas. There are people doing acupressure. There are people doing music therapy. We had some people tell us music thanatology is different from music therapy [laughs]. So, they wanted to write about that. They wanted to say, “I want you to know about the complementary therapy that we are offering.” To be able to help such people write about what they're most interested in to give them a platform in a book that's gonna' be published to help them write an article for the ChiPPS E-Journal, that's very satisfying for me and I hope very useful for other people.

Bryan Sisk: Yeah, I almost in the way you're describing your career, I almost see parallels in the modern bioethics movement where the concept of strangers at the bedside then became integral to the whole process. Where there other people like you that were doing this in pediatric palliative care?

Charles Corr: Well, there are a lot of people these days now doing some aspect of pediatric palliative care and you probably have a whole list of them that you're going to interview. The folks at Akron for example or gosh, the folks who are the providers and Christy Torkildson in Oakland. There are just so many doctors, too, Hal Siden at Canuck Place. Gee, I know there are just so many names you could mention of people who doin' very good work and who are trying to teach other people about it, Brian Carter, Steve—what's Steve's name in Montreal?

Bryan Sisk: Liben?

Charles Corr: Yes, Steven Liben. So there just are a lot of people and now. What I would say if I tried to get into this field now, it would be completely different because there are people who know way more than I do about whatever specialty they are focused on. What I knew or learned at the very beginning was a kind of very broad overview of issues related to hospice care, palliative care, children, adolescents [coughs]. For example, we did a book on sudden infant death syndrome. That's changed since our book, but at that point, the people who were doing counseling for parents who had a child die almost instantaneously from a cause that no one really understood properly and maybe still don't, that was very interesting for me to know.
I wasn't a support person or a counselor for such parents, but I was a guy who tried to learn from them. Yeah, there were I don't know. It's been a very interesting career. It's not somethin' I ever planned and it's probably not typical, and if you said, "What were things like, I don't know, in the mid-70s and what are they like now?" it's night and day. It's completely different and there's a lot of really great work being done to help families and children and adolescents.

[00:41:19]

**Bryan Sisk:** When you say things are completely different, what parts are you referring to?

**Charles Corr:** Well, first of all, a lot of the disease entities have changed a great deal, childhood cancer, for example, as you probably know better than I do. New diseases have arisen like HIV [human immunodeficiency virus]. When we did, we eventually got around to doin' a textbook for a course on death and dying, we probably waited about, I don't know, 15 years before we had enough courage to try and do that. When we did the first edition of our textbook, which was published in the early 90s, I think we thought there was never gonna be a cure for HIV and people were gonna die very swiftly with very short trajectories and now, it's a completely different scene. A lot of things have changed.

There are a lot of good bereavement support groups that were not available at all. There are people who say, "Yeah, but there's not a support group for my kind of bereavement," and that's true and maybe not in every location; easier to have them in highly populated areas, but still there are supports. There are now supports on the internet for folks. You can learn a lot about various kinds of illnesses, various kinds of diseases, cure-oriented intervention, palliative care, just by sittin' down at a computer. None of those resources were available. I typed out manuscripts for articles and books [laughs]. I wouldn't even think of tryin' to do that now. You could write 'em, write 'em out because I made too many mistakes when I was typing.

[00:43:16]

**Bryan Sisk:** Wow.

**Charles Corr:** Computers make that easy to make corrections. Sometimes the machines will correct for themselves for you. I think your question to me was how are things different? They are different in so many ways over from the mid-70s to the now the second decade of the 21st century.

*[Extraneous conversation 00:43:44 – 00:44:13]*
We were talking about all of the differences. I guess another way of thinking about it, are there any things that are the same from the 70s until now?

Well, [laughs] there are people who are dying [laughs]. There are children who are dying and there are children living with life-threatening conditions. Chris Feudtner once wrote recently—that's another great doc for you in Philadelphia. He once wrote recently that one main difference between adult and pediatric palliative care is that the children who are admitted to pediatric palliative care are often alive a year later. I thought that was stunning. You're thinkin' of a different kind of population not one that's dying imminently right away, but people who are living with the, what do they call it, complex medical conditions some of whose complexities are way beyond me, probably are the kind of thing you are studying. But there is care that can be offered to such children and to their families. That's an important difference.

From your perspective—

They're just ignored.

From your perspective, what was the big driver for the development of pediatric palliative care as a specialty?

What was the big driver? I think unmet needs. I think people looked at families and thought here are families suffering. Here are children suffering or adolescents suffering and their needs aren’t being met and it's not enough to say we've tried all the cure-oriented interventions and now, that terrible language "there's nothing more we can do" needs to go away because there's always something more you can do either as a clinician or as a fellow human being. I think the big drive was for so many alert, sensitive clinicians. They began to realize that they weren't meeting needs.

If you go back to the origins of the adult hospice program, you had for example, Bal Mount in Montreal did surveys at the Royal Victoria Hospital and he discovered there was a lot more pain than everyone wanted to admit, so unmet needs and that's a urologist who became the leading palliative care physician in Canada. I think people became sensitive to, "We were not doin' as good a job as we thought we were," or "We're not doin' as good a job as we could do if we tried to do better."
**Bryan Sisk:** How much do you think the adult hospice movement affected the development of pediatric palliative care?

**Charles Corr:** Yeah, I think it spilled over. I think the philosophy behind hospice care animated palliative care and so, people realized that holistic care or the kind that the hospice stood for could move palliative care units, which are largely in hospitals and those two movements made pediatric people think what can we do to achieve more holistic care? As I said earlier, I think pediatric folks were more sensitive to holistic care, to family care, to family units. So they needed to find ways to implement better care for the child and the family and the other kids or grandparents or whoever it would be that were involved with that child. I guess I would say unmet needs, words to that.

**Bryan Sisk:** Do you think there were any negative influences from the adult movement onto the pediatric movement?

**Charles Corr:** Negative?

**Bryan Sisk:** Yeah, were there any things from the adult movement that hindered the development of the pediatric movement?

**Charles Corr:** I don't think I know how to answer that question. It's an interesting question. Were there ways in which the adult movement—I guess I've always thought about the positive things that came over to pediatric care or that sprouted out of pediatric care itself. I'll have to think about that question. I don't have a good answer for you right off the bat.

**Bryan Sisk:** What about going the other direction, can you think of any examples where the pediatric palliative care movement had influences on the way adults were cared for?

**Charles Corr:** Well, it reinforces adult care. If you can care in better ways for children and if you can care in better ways for their families, then that's the standard for adult care, not only for the care of the ill adult, but for the care of the whole family surround. It asked us to pay attention to all the people who are involved and also to the clinicians who are delivering care because they, too, have coping issues and they need support of various kinds. I think in those kinds of ways, yes, pediatric care does help you know and people used to say early on to the hospice movement, "I don't know how you can do that work that you do." Well, they still say it to pediatric [laughs] people.
I suppose you've heard that and yet, most hospice people that stay at it for a while say, "This is very satisfying work to me. I'm really doing something meaningful." I had a pediatric social worker say to me one time in St. Louis, "Do you know what it's like being a social worker in a mental health facility? People throw clocks at you. They curse on you. They spit at you. What is like being a hospice social worker or a palliative care social worker? People say, "Thank you very much for trying to help my family member."" I thought wow, that's impressive. People did not expect care would be helpful to them and they found that the clinicians could help them in important ways and they're grateful for that.

[00:51:43]

Bryan Sisk: In closing out here, where do you think the field of pediatric palliative care has the most room for growth or the most need for growth now?

Charles Corr: Well, what I hear in terms of the ChiPPS E-Journal and our workgroup that produces that thing is one of the major issues is transitions, transitions from home to hospital, transitions to long-term care, but also transitions from pediatric to adult care. [coughs] And so, interesting issues seem to arise about young adults. You may know that Helen House in Oxford in England, which started as a respite care program for children and for their families, built a second facility, Douglas House and that's for young adults.

They began thinking about what about people who are in their late teens, early 20s. What kinda care do they need? What's special about their needs? Who's gonna deliver that care to them? Are they just gonna be shunted from a pediatrician who has followed them and really knows them to an adult care provider who may not have much experience with the kind of issues they are dealing with? My impression is that's one of the major challenges these days, is in effect expanding the scope to include young people.

[00:53:28]

Bryan Sisk: Well, those are the questions that I had, but is there anything else about especially this early history that you think I haven't asked about?

Charles Corr: No, I think you've done pretty well.

[End of Audio]