

Biography

Barbara Sourkes, PhD, a child psychologist, is the first John A. Kriewall and Elizabeth A. Haehl Director of the Pediatric Palliative Care Program at Lucile Packard Children's Hospital Stanford, and Professor of Pediatrics (and by courtesy, Psychiatry) at Stanford University. In addition to many articles and chapters, Dr. Sourkes has published three books: *The Deepening Shade: Psychological Aspects of Life-threatening Illness* (1982), *Armfuls of Time: The Child's Psychological Experience of Life-Threatening Illness* (1995), and (with Michel Hanus, MD) *Les Enfants en Deuil: Portraits du Chagrin [Bereaved Children, Portraits of Grief]* (1997). She also co-edited (with Drs. Joanne Wolfe and Pamela Hinds) *Textbook of Interdisciplinary Pediatric Palliative Care* (2011). Dr. Sourkes served as a member of the United States Institute of Medicine Committee on Palliative and End-of-Life Care for Children and their Families. She has won several awards, including the Outstanding Clinical Care award from the American Psychosocial Oncology Society (2011), the Humanities Award from the American Academy of Hospice and Palliative Medicine (2014) and the Compassion in Action Award from Hospice of the Valley (2016).

Interview Abstract

Dr. Sourkes attributes her career beginnings in pediatric palliative care to a "confluence" of personal and professional experiences. She describes knowing a few "pioneering" health professionals in the 1970s and 1980s. In different fields and different countries, these "first-generation" professionals were all working on their own to commonly define pediatric palliative care and its place in healthcare.

Dr. Sourkes recounts the early days when, in many hospitals, a handful of social workers took on all the psychosocial care of hundreds of children and families in pediatric hematology/oncology. Dr. Sourkes briefly discusses working with Balfour Mount MD when a group at the Montreal Children's Hospital was developing an interdisciplinary pediatric palliative care team. She discusses psychology/ psychiatry's early role in understanding and interpreting childhood expression of suffering. At the time, despite the distress of families and healthcare professionals witnessing children experiencing pain, it was thought of as a "necessary evil" related to the use of intensive treatments. She then explores an apparent early divide in psychology between research and clinical understanding of dying and suffering in children.

Dr. Sourkes reflects on her hospital experience in the 1980s and 90's at the Montreal Children's Hospital working with children and young adults with hemophilia who, as a result of treatment with blood products, were infected with HIV. Another group were child-refugees from Rwanda and Haiti, who had escaped unspeakable horrors, only to find out that they had been infected with the virus. She relates her experiences working with these especially vulnerable populations as having profound impact on her understanding of the complexities and influence of palliative care on a person's healthcare. Dr. Sourkes describes her challenges to change language describing palliative care - and its benefits in a patient's life to achieve the optimal health outcomes. Out of these clinical challenges, Dr. Sourkes was inspired to write her landmark books *The Deepening Shade* and *Armfuls of Time*.

Dr. Sourkes concludes with her two visions to further the field of pediatric palliative care. The first vision is to understand childhood suffering by exploring children's expression and voice in their own health care. The second is to create and expand a narrative of pediatric palliative care that is educational and less overwhelming for institutions that interact with children, including schools, community centers, religious institutions, as well as the public.

Glossary of Acronyms

<i>Abbreviation</i>	<i>Definition</i>
AML	Acute Myeloid (Leukemia)
Heme Onc	Hematology Oncology
HIV	Human Immunodeficiency Virus
IOM	Institute of Medicine
PACT	Pediatric Advanced Care Team
PICU	Pediatric Intensive Care Unit

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****Edited for grammar and content by Professor Sourkes. Additions and redactions indicated by brackets and ellipses, respectively.****

[00:00:00]

Bryan Sisk: Today is June 19, 2019. I am Bryan Sisk and I am in St. Louis, Missouri, interviewing Dr. Barbara Sourkes over the telephone for the pediatric palliative care oral history project. Dr. Sourkes is in Palo Alto, California. Thank you so much, Dr. Sourkes, for your joining me today. To get us started, could you just tell me when your mind first turned toward palliative care as a career focus?

Barbara Sourkes: As a career focus, back in 1975. I think that like everything [important], there's always a confluence of the personal and professional. In 1975, when I was at University of Pittsburgh finishing my dissertation, a seminar was offered by a well-known family therapist named Lois Jaffe. [In addition to her regular courses, she had added one of the very first interdisciplinary seminars on working with patients living with life-threatening illness and their families.] What was particularly “intriguing” was that she had recently been diagnosed with AML and was... teaching from both her personal experience as well as through a professional lens. It was a remarkable, remarkable seminar. There were probably 15 or 18 people from every discipline. My interest was already in that area, because of my own family loss history. I'd read Kübler-Ross and others—I was already geared toward this. That seminar led to a friendship with Lois, and in the next few years, we did some writing together. In fact, we planned *The Deepening Shade*¹ together, but I wrote the book on my own after her death.

That was 1975, and that seminar really launched me. Later that year, I left for Boston Children's Hospital for my internship. I went with a very intentional request - that I be allowed to work in pediatric heme onc, which at that time had almost no psych consultation. As part of my predoctoral and postdoctoral work there from '75 to '77, two colleagues and I set up the psych consultation system within pediatric hematology -oncology, and from then on, I never looked back. That's been my field ever since.

[00:02:59]

Bryan Sisk: Not having many psych consults, was that common across the country, or was that something unique to—

Barbara Sourkes: No. No. It was the state of the art. This was at the Dana-Farber Cancer Institute / Boston Children's Hospital. There were two social workers working with hundreds of families. They were just trying to put out fires or arrange very concrete needs. Even though these two social workers could have been doing counseling and

¹ Sourkes, B. (1982). *The Deepening Shade: Psychological Aspects of Life-Threatening Illness*. University of Pittsburgh Press.

therapy, they were stretched much too thin to be able to. There was a psychiatrist from the adult service at Dana-Farber who was available for emergencies. By that, it would have meant a child perhaps with extreme delirium or a suicidal child. As you can imagine, he did very few consults and wasn't at all integrated into the pediatric team. This was common. Most teams at that point had social workers who were almost always overloaded, but child psychology and psychiatry were not much involved. We were late to be invited, but also late to initiate being in the game.

By '76, we had actually three psychologists, and it grew from there. We saw some patients on referral, and I think the ones we saw absolutely *not* selectively were the children with bone tumors who were going to have an amputation. Those, we were asked to see all of them. It was the state, it was the way it was. There was not much attention paid to the psychological experience of the children until around then.

[00:04:52]

Bryan Sisk:

That's interesting because looking historically at all of the publications about children that were dying and suffering in various ways, for the first two decades, almost every publication that was on this were from psychologists or looking at psychological distress. What do you think led to that clinical and research divide?

Barbara Sourkes:

You know what, Bryan? I don't know. Yes, I know some of the early writers. There was a disconnect between the fact that psychologists were writing some of these seminal articles, Spinetta and others. But the allocation of clinical services in the institutions was very different... It was mostly an on-call model, with usually a solo psychologist or psychiatrist trying to cover it all. I can't explain it. I think it was just pioneering times, frankly.

[00:05:56]

Bryan Sisk:

When did the concept of having a psychologist with the pediatric hematology oncology team, when did that transition into this concept that your career should actually focus more broadly on the palliative care?

Barbara Sourkes:

In '75, about 70 - 80 percent of the children with cancer died, and 20 - 30 percent survived. Now, of course, that statistic has flipped. While we did not call it "palliative care" at the time, most of our patients did die. Pediatric palliative care, in a sense, started in oncology without it being called so. But really, in fact, that's what it was, a very different landscape.

[00:06:52]

Bryan Sisk: It sounds like clinically, you didn't have a lot of psychiatry, psychology—

Barbara Sourkes: Hmm-mm.

Bryan Sisk: - they weren't around. Were there other people of similar minds on the needs and the suffering and what needed to be addressed—

Barbara Sourkes: Yes.

Bryan Sisk: - at that time?

Barbara Sourkes: There were. There were. There was a beginning insistence on the clinical involvement [and focus on psychological issues]. And those of us in the field were aware of one other, but we weren't necessarily connected. I knew Myra Bluebond-Langner's work. She's an anthropologist, not a clinician, but I certainly knew her work before I actually met her. Jonathan Kellerman (you may know of him since he's written about 30 best-selling thrillers at this point!), but he started out as a child psychologist in Los Angeles, and he was sort of my West Coast counterpart.

There were a few other psychologists at the time whom I knew. Gary Walco was specializing in pain management as was Leora Kuttner. Lonnie Zeltzer, a physician in L.A. [Los Angeles] shared that interest, particularly in adolescents. There were more people than these, but these are people whom I knew. I can tell you - we were few and far between at that point.

[00:08:10]

Bryan Sisk: Did you guys find ways to come together, or did you just peripherally remain aware of each other?

Barbara Sourkes: It started to integrate, I'd say, in the late 70s in terms of at least meeting one another. Jon Kellerman in, I think it was '77, wrote a letter to a bunch of people—none of us had met—we only knew about one another—saying, "I want to edit a book on psychological aspects of childhood cancer. What would you like to write about?" That was literally what it was. [laughs] It was an excellent textbook. Some of it is still highly relevant... There wasn't even e-mail, but we were starting to get to know one another.

There were meetings occasionally where we would meet up. I'd say it was the late 70s that the desert began to have a little more flowering in it. I was connected with people in the adult world - partly because I came from Montreal where the first in-hospital

palliative care service ever had been set up by Bal Mount, whom I knew well. I knew a psychologist at the Université de Montréal who had done some research in bereavement named Margaret Kiely. However, they knew zero about pediatrics! There was a collegueship there, although the focus was different.

The other field that started developing at that time— [in the mid to late 1970's] - also adult first, was at Sloan Kettering under Jimmie Holland, a psychiatrist. She and her group [of psychiatrists and psychologists] coined the term “psychosocial oncology” – which has now become a field in its own. Those were people that I had a lot of affinity with, but not in terms of pediatrics. Pediatrics came in more slowly.

[00:10:21]

Bryan Sisk:

You've mentioned largely researchers, anthropologists, and psychologists. When did other professions come in, like when did nursing start to come in? When did physicians start to come in?

Barbara Sourkes:

Nursing, people like Betty Davies, we were all first-generation. [laughs] Betty and I were at the International Congress [of Palliative Care] in Montreal, I think it was 1983, that we were on a panel together. Late 70s, early 80s is when there was a *beginning* of a pediatric presence beyond just very scattered individuals. Beginning. [laughs] It wasn't even a question of mentorship so much as developing, inventing things together as peer colleagues because it was such a new field.

[00:11:15]

Bryan Sisk:

Who did you learn from as you were going into the frontier?

Barbara Sourkes:

[laughs] A lot by the seat of my pants. I got really excellent training in psychotherapy and evaluation in general, but what I carved out in terms of developing—and again, initially in children with cancer—was new territory. It was really new territory. People certainly had done it, but again, not much writing about it, not much consistency. I always say, you can't do this work without basic across-the-board training in working with children, whether it's pediatrics or whether it's pediatric psych. I had that, but it was kind of a self-discovery route and trading ideas. I can't say that I knew anyone ahead of me in doing this kind of work in pediatrics. No one I knew. Just colleagues.

[00:12:18]

Bryan Sisk:

Were there a lot of people that were doing the work clinically, but not writing it up, or was everybody that was navigating this also writing it up and publishing on it?

Barbara Sourkes: You know what? Anything I say now is—I'm sometimes guessing. I don't know. Psychology, psychiatry were not very involved clinically. I really have to say that and I'm ashamed to say it. Danaï Papadatou, [a psychologist in Athens], Jon Kellerman, and I were writing—you can count the individuals. These fields were slow to join in, and many places—partly for lack of funding, partly just not recognizing the importance. Mental health and many other needs were covered by social workers who were stretched beyond all limits., Child psychology / psychiatry were really more for crisis, call them in when things have gone further. It was late before we, the mental health professionals who specialized in children, became visible and integrated. And we still struggled in terms of having people understand what we do and what makes it different, what makes our contribution unique from other members of the team.

[00:13:36]

Bryan Sisk: One thing that I was struck by in some of my other interviews is how heavily indebted this field of palliative care is to social workers and psychologists and nurses as the driving force. Another thing that struck me is, talking to some of the people you had mentioned that were really first-generation, when the concept of hospice, which was more easily understandable, transitioned into the concept of palliative care, someone told me that there was a little bit of hesitance that this might have been doctors trying to take over the field. Was there some of that hesitance you were aware of?

Barbara Sourkes: I can speak to that sort of culturally. I grew up in Canada. What I knew and could see was that the pioneering in palliative care, adult or pediatric, was in England, right? It was Cicely Saunders, and eventually, it was Ann Goldman in pediatrics. The commonwealth countries particularly in this case Canada, Australia, were pioneers in the in-hospital palliative care units - the palliative care name and concept. Those were mostly founded by physicians and nurses. What was going on—starting in the late 60s, what was going on in parallel in the U.S. [United States] was community home-based hospice. There certainly were physicians involved, but the pioneer people were from social work and nursing, with a link to physicians.

It's really interesting what's happened. The in-hospital, maybe more academically-based palliative care was first in Britain, Canada, Australia - and the community grassroots home care and hospice developed early was U.S. Over the years, obviously, there's been a confluence. I think that there is a concern in the field

that, as “palliative medicine” develops as a field [rather than “palliative care”], that people are forgetting the roots, and the roots were absolutely nursing and social work. I wouldn't put psychology in there.

I react myself when suddenly people start talking about the field of “palliative medicine.” It's a field of palliative medicine for the physicians, but if we are true to an interdisciplinary vision, which I'm afraid we may be losing, but if we remain true to it, then it's broader. It's whatever you want to call it, palliative care, palliative treatment. I think that's when people feel like, "wait a minute, wait a minute. We were the pioneers, and now we don't really get named in this." That's my view of the history.

[00:16:36]

Bryan Sisk:

Another interesting thing on this history is how much of the landmark initial pioneering was in the U.K. [United Kingdom], like you spoke about—

Barbara Sourkes:

Yes.

Bryan Sisk:

- but then the research engine really shifted to the U.S. as—

Barbara Sourkes:

Mm-hmm. Mm-hmm.

Bryan Sisk:

- where all the research, all the publications were coming from. Do you have any insights into what was driving that shift?

Barbara Sourkes:

Let me think. In pediatrics? I'd say, to some degree, cultural. I think it's cultural and time. The pioneers were just figuring out how to set something up in a hospital, and they didn't get as far as the research in those early years. I think the culture certainly in academic institutions here in the U.S. is very much research-based and always has been. I think it wasn't a question of ‘all or nothing’ in either direction, but the emphasis in Britain was, "this is the concept, and this is how you develop it." Here, there was that concept, but from the beginning, added: "we need to be investigating this." It took us a long time to get going, but the push toward the research was more explicit here, I would say.

[00:18:00]

Bryan Sisk:

Now thinking back to when you were beginning your work, what do you think—both in psychology and also in general in the care of these kids, what do you think were the biggest challenges in caring for these kids that were suffering from these severe illnesses?

Barbara Sourkes:

That there was very little focus on symptom management, on pain management. When I think of what the kids went through in the

70s, no sedation for many procedures, whether it was bone marrow, spinal taps, whatever. [Little emphasis on symptom relief in general.] I think that everybody, families and professionals, somehow just felt that the pain was kind of a “necessary evil” of the whole treatment experience. There was great distress about it, but it really took time to be addressed. It started partly with people being interested in nonpharmacological ways of helping the children manage. [In that area, Leora Kuttner was influential.] I did hypnosis training in, I don't know what, '80, I think, 1980.

But with the use of psychotropic medicine and pain medications, there was a general resistance, as there often is: "We shouldn't be giving these in general", and then especially not to children. It was a huge challenge because it just didn't seem right [to withhold these medications], but it took time for people to really begin to focus on symptom management.

Oncology in that period, the 70s especially, things were happening so quickly in terms of new treatment. There was a lot of excitement about the acceleration. I think the focus on the "whole child" got lost in that. There's a balance. I think the reason for the excitement was because children were starting to *live* with this illness. That took up a lot of people's attention.

One of the things you asked, "were children and parents involved?" Yes, they definitely were. When I think back to families and children, the conversations were not so different from what we have now, but I would say the lens was different. We did not have the specific conceptual lens on the vicissitudes of decision-making and of explicitly listening to the child's voice. It all happened, the conversations happened, but not with the sort of awareness that we have now...

[00:21:06]

Bryan Sisk:

One thing that's interesting to me about the presence of pain in these kids is that, to some extent, I've read and heard that there was a lot of distress in doctors, but especially in nurses that were caring for these kids when they were seeing how much they were suffering. But at the same time, there was evidence of misunderstanding or a lack of appreciation of how much pain they were in. What was that balance? Were people not recognizing it? Were they recognizing it but not recognizing it was as bad as it was? Was this a defense mechanism so that they could handle it?

Barbara Sourkes:

I'd say all of the above. There was distress and, as I said earlier, there was a sense of helplessness because people hadn't formulated, where do we take this? The sense (where the change

was happening), was that this shouldn't have to be a "necessary evil" of these kids' treatment. It's not good enough. There was a lot of concern about opioid use among professionals. There was not a lot of education about it, and people felt that it was definitely only for use at the end of life. It was not something that you might routinely use in symptom management.

The intentions were there. The distress on the part of the staff was there, but it only then began to crystallize into, "We really have to address this." Things as they were then - they'd be unacceptable now. The sedation and so on that we use now, there was little of it, so [the children experienced more pain – that made it] a much more fearful experience for them.

[00:23:03]

Bryan Sisk:

It seems like psychological issues would be not as front-and-center and harder to pick up. Were they as recognized? Was it similar to pain where the psychological concerns were recognized, but there just wasn't a way to address it and it was accepted, or was it that people just didn't recognize that it was an issue?

Barbara Sourkes:

Both, I'd say. Both because there was no template for this. I think it was in those very pioneering years that people doing either the research or the clinical writing were saying, "These children are thinking, feeling a lot of things, and they're expressing it. They may not be expressing it in conventional ways, but you have to listen." I think it wasn't that people were dismissive of it. They simply didn't even know what to ask or what to listen for or how to understand children's form of expression - whether it was drawings or stories. Often children would be telling you a lot about their awareness, but people often didn't recognize it as such.

It's staggering, as you know, when you hear what comes out of the mouths of kids, but it really was staggering to people then. As we [psychologists] were working with the children, we were able to, at rounds say, "And this is what the child is saying about the experience." People just hadn't heard this before - because they hadn't known how to either ask the questions or understand the answer. I can't tell you. What do you call it when do you a fast-motion video? It's like things were happening—

Bryan Sisk:

Time lapse?

Barbara Sourkes:

Yeah, time lapse. Whether it was the progress in the treatments over that period of the mid-70s onward, and in parallel, the awareness of the psychological - it was just happening fast on a lot of fronts, and a very rich time in that sense.

[00:25:18]

Bryan Sisk: Was there a concept or an awareness of suffering in itself in these kids as a concept, or was it more so the awareness as it existed was of symptoms individually?

Barbara Sourkes: There was some awareness of the holistic sense of suffering. There was some language for that. There was both, Bryan. It depended often on the individual, the person. Teams recognized both, and teams tended to feel (and I'm being generic when I say teams), but—very impotent in how to address these things with kids. I do think that that's where the entry of child psychology / psychiatry made a difference in explaining and interpreting and bringing that aspect of things into focus. It's not that people were insensitive or anything...

People were aware children were suffering, but in the sense of the adult world where you talked about “total suffering”, that kind of palliative concept, it wasn't there. It's developing now, I'd say, but it wasn't there then in the same way. As a culture, it wasn't there.

[00:26:59]

Bryan Sisk: What about personally? What were the biggest personal challenges you faced as you were trying to build this career?

Barbara Sourkes: I think really from the beginning, and to some degree, it continues, is having the unique contributions of child psychology / psychiatry be recognized. That psychotherapy is *treatment*, and that it's unique and different from “support.” Everybody offers support [– but that is not the same as treatment.] I think that's an ongoing struggle for the mental health contingent in this field...

I don't think there's good understanding of, so what do psychology / psychiatry—I put them together for now—do? Maybe it's partly our fault in terms of not explaining it better. My sense is that when children in palliative care, have really specialized medical and nursing assessments, they should, in the same way, have a specialized psychological status assessment – certainly if you're really planning for optimal care. I think that evaluation and diagnosis of psychological symptoms and disturbance, the recognition of the role of psychotherapy and psychotropic medication... still are under-recognized. [The use of medication has made more of an inroad than psychotherapy.] Certainly, at the beginning, all of this was foreign.

There's been some progress, but I'd say at the beginning, that was a really huge challenge for me, for the small group of us...

I was at Dana-Farber and Boston Children's for 13 years, and then in late 1996 I got a call from the Montreal Children's Hospital. They had a regional hemophilia center with 300 patients, almost all of whom were severely affected. The reason that they had such a preponderance of people with severe hemophilia is they were the first to do home factor infusion, so people were referred there from far and wide...

On that call I was told: "We need help for the staff at the hemophilia center." These individuals had "signed on" to work with chronically-ill children and adults with wonderful new treatments happening. [However, it was these very treatments that led to many patients developing HIV, and as a result, the clinical practice of chronic care was turning into a practice of palliative care.] That's not what the staff had signed up for, and they didn't have any coping mechanisms for this drastic change. [Of the 300 patients, about half were infected with HIV.] Many people had been there a very long time and knew generations of patients and families... I moved to Montreal in late 1987 specifically to work in that center.

If you asked for one of the biggest challenges in my whole professional life, it was two populations, and this was one of them. Working with the group of people with hemophilia and HIV, where families sometimes lost three, four, five members. It was just unbelievable. It was early in the HIV epidemic... It was a particular time in history, really, the mid-80s, when everything in that field was a clinical challenge, and it was a legal challenge, and it was an ethical challenge - because of all the issues around tainted blood. I remember thinking to myself - this makes oncology look easy - it's unbelievable. The psychological complexity for the children and families and for the staff was just enormous.

The other group that was a big challenge at the same time was a group of refugee children, mostly from Rwanda and Haiti. These children had lived through the most horrific experiences and managed to get out with some part of their family [only to find that they were infected.] . Many came to Montreal because French was their language. Those two populations pulled me right out of the oncology world and into something that had reverberation of a different degree to me. Those were the biggest challenges for me, figuring out how to make my own field understandable and valued and then just realizing that the depth of complexity in palliative care was sometimes beyond what I'd imagined.

[00:33:08]

Bryan Sisk: That's when you branched out from oncology—

Barbara Sourkes: Yeah.

Bryan Sisk: - and hematology and rightfully perceived that that was palliative care. When did the field—this is also as it was developing, but when did the field of palliative care recognize and start to branch out beyond oncology?

Barbara Sourkes: In *pediatric* palliative care, right from the beginning. The first program in the U.S. was Boston Children's in '98. However, there was a nurse at Toronto Sick Kids who in, I believe, it was 1990— (and I wish I could remember her name – and that I still had her brochure). I think she had 10% of her time for palliative care, and she actually put out a brochure saying “pediatric palliative care consultation.”

This was the first hospital-wise initiative. She was a pioneer... We at Montreal Children's, we had the adult model just with Bal Mount's department. We pediatric people actually came together in 1990, and I think had the first interdisciplinary team in—starting in '92. We had a hospital-wide program from the beginning. A physician named Robert Hutcheon, whose particular specialty was working with children with thalassemia, was very intrigued by palliative care [and became the first medical director of our program.] It was a physician, a nurse, a psychologist, a social worker, a chaplain, and a psychiatrist who comprised our initial group. We took consults from throughout the hospital, and the service grew. In some ways, that's what led to my then coming to Stanford because I already had the experience of participating in setting up such a program... What we set up was *not* oncology-based right from the beginning. [The next medical director was Stephen Liben, a pediatric intensivist.]

[00:35:12]

Bryan Sisk: A lot of the history of this field seems to be people doing good work that would eventually be recognized as palliative care over time coalescing into a profession and a discipline.

Barbara Sourkes: Yes.

[00:35:28]

Bryan Sisk: From your perspective, what was the big driver that pushed that movement along?

Barbara Sourkes: I think that... as children with many different diagnoses were living longer, people recognized that whether the child ultimately

died of the disease or not, the complexity of their care was enormous... ["Palliative needs" were emerging, and they were emerging as their own entity as people witnessed children's experience. People began to focus more holistically on the child and family.]

During the later 80s and the early 90s, there was more writing about the children's experience of illness. The child's "voice" was louder and more insistent in some ways. I think that as children lived longer, people got to really witness and understand their experience. I think that awareness was sort of a general clinical driver of the field.

I think that the Institute of Medicine² report was really critical. I was on the committee. The Report came out in the early 2000s. It was interesting because the Dean of Medicine here at Stanford at the time, Phil Pizzo, a pediatrician, had chaired the IOM report on palliative care for adults.

When that report was done, he said, "Now we owe it to - we need to do a study for children." The pediatric IOM committee met from, about 1999 to 2001. The IOM of course, prides itself on being very research evidence-based. The paucity of research at that time [in pediatric palliative care was] - it was crazy. People were *searching* for references. The ultimate report, which runs about 700 pages, is huge because there were not many citations of research. If you look at it, many topics say, "Expert clinicians tell us," or, "From clinical experience," - and there is a long narrative - because there just was not a research base at that time. The committee recognized that this was a different kind of report...

I think that the IOM report was a huge driver. It had huge impact on defining the field of pediatric palliative care, and it really set an agenda. In the years since then, this field has taken off clinically as well as in research and education.... I'd say it was very meaningful.

[00:39:28]

Bryan Sisk:

What do you think has been the role of funding in this development, both funding from philanthropic organizations and then also funding in terms of getting reimbursed for a clinical service?

Barbara Sourkes:

I'll start with philanthropy cause that's the one at Stanford I'm familiar with. Here, our program is very much—not entirely - but very much philanthropy-based. [For us, that has been critical.]

²When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families by Institute of Medicine, Board on Health Sciences Policy, et al. | Feb 9, 2003

I think the process of fundraising has been really interesting. Even before I arrived here officially, I met with some potential donors, as we were looking for funding for a program directorship position. One of the dilemmas was that we had several donors who were taken with this new field of palliative care, but who then ultimately said, "This is wonderful. This is important. But it's too sad," and chose something else to fund.

What we began to realize is that maybe how things were being presented was part of the problem. If people thought that we only were going to see imminently dying children... then obviously, we weren't communicating something that had some light and hope in it. What changed is that we did a lot of education with the staff at our hospital foundation. Lots of in-services talking to them, giving them the language, explaining the spectrum of what pediatric palliative care was. As they became more comfortable with the subject, they were able to present it in a way that wasn't as frightening. [I've talked to people from other places, and I've so much emphasized that between you and the donors is the foundation. If the foundation isn't comfortable talking about this, it's not going to happen.] I think philanthropy-based is—for us - it's been critical...

In many places, the palliative care programs are considered one of the “gems” of humanity and value and compassion. But many programs are really scrambling to have the funding to match that pride. The reimbursement issues are really difficult... Everything had and still has to be created, and it's been slow. For example... in terms of billing, if things don't fit a certain template, there's just a lot of consternation about, what do you mean? What is a palliative consult, and what's a follow-up? When do you call it psychotherapy, and when do you just call it a follow-up? It's trying to understand it, but it's been a very slow process to translate into a good billing system...

[00:44:12]

Bryan Sisk:

When we were talking about the role of philanthropy and some of the problems with the foundation, it struck me as a marketing problem or—how do you paint the field so people understand it? How has that same problem evolved with—when interacting with patients and families and when interacting with other clinical teams? How has that marketing issue been a problem?

Barbara Sourkes:

It's been interesting here. Across the country—many programs call themselves PACT, and others call themselves “palliative care,” and then there are assorted other names. I came out of Montreal- the origin of the palliative care movement. As long as I'm here, we're

calling it what it is, "palliative care." From the beginning, we got a lot of warnings, like, "You don't really think you're gonna get referrals if you call it that?" We said, "Let's try it." It has taken a lot of education of our colleagues and of the families, and then demonstration of what we actually do.

It's been, if you refer this child to our team, let us show you why early referral is helpful. Let us show you what our service means. Only a small proportion of our patients are imminently dying. We follow children for years. That kind of real-life education has taken a long time. I have no way of knowing how many referrals—this is just at the colleague level—we've lost over the years because of the name. We certainly have lost some, but we've kind of gritted our teeth and stayed with it. Now, in the hospital, people talk about palliative care. It's just sort of, "Yeah, let's call the palliative care team." They're used to us in general, but there are still pockets that say, "Couldn't you just change your name?"

One of our team's most interesting conversations was about four or five years ago with colleagues in cardiology. We did not get referrals from them at that time. One cardiologist asked, "Why would we refer to palliative care? This kid's on the transplant list." And we said: "Because prognostic uncertainty is sort of a definition of when palliative care is appropriate. That's wonderful that children are on the transplant list. But they have to live long enough to get to transplant. They have to survive the procedure. They have to get through all these things - "

The same cardiologist looked up and said, "I think it would really help if you changed the name of your team." I retorted, "You know what? I think it would really help if you changed the name of yours - the heart *failure* team.???. Is that name really so optimistic compared to ours?" It was funny. [*laughs*] We all burst out laughing. Now, more than half our referrals are from cardiology.. That interchange was interesting because... even within my team, people were saying, "Are you sure we shouldn't change the name?" I said, "When you have a new director, if you're all still here, you make your decision." I'm usually really democratic, but this decision is true to me.

I was at the International Congress in Montreal a few years ago, and I was sitting with Ann Goldman. One of the speakers was talking about the impact of using the name "palliative care" for a program. Ann leaned over to me, and said, "For God's sake. A rose is a rose is a rose. By whatever name you call it, the families know

exactly who you are!" [laughs] I said, "Yeah. I think it's all in explaining."

Starting out, Bryan, I did not know how we were gonna explain ourselves to families. It was a very organic process of figuring it out, and as I talk to others in the field, , I think we've all evolved similarly.

We found that when we first went in, some families just looked at us with that look of terror and said, "Aren't you just hospice?"

That was actually a helpful opener, because sometimes, defining things by what they're NOT, can be more powerful than stating what they ARE. We could comfortably say, "Absolutely, we are NOT just hospice." I would say, "Palliative care is a very broad, broad field, and hospice is just this little small slice at the very end that some children reach... and many do not." I would even use my hands to demonstrate. Then people would at least continue to listen... When people ask us, "What does your team provide?", we begin with "Decision making... helping you to clarify decisions, making sure things are explained to you, advocating for your goals"

Then a really key thing happened. It was another one of those "ah-has." I was talking to the family—of a child with a complex chronic condition who had been admitted multiple times. I said, "You've already had to make so many critical decisions for your child. Now you're in the PICU [Pediatric intensive care unit], and you're making decisions again. We're here to help you right now - in the present and - *into the future*." In those three words, something changed. Now we always say, "We're gonna help you with decision-making in the present and into the future." It's the power of language. You see people change. So we talk about decision-making. And then we talk about pain and symptom management – ensuring that “your child is comfortable, no matter which treatment pathway you choose.”

The third point is psychological guidance, “we have two psychologists on the team—guidance for you around your children, both the patient and the healthy siblings... Once we get in there and explain, families are very accepting because those are things they really need. In turn, when we haven't gotten referrals, occasionally, a colleague will say, "I really, really told this family about you. But I couldn't get them to agree to meet with you." Then we ask "What did you explain?" That's where the education is critical to teach colleagues how to explain our role in a way that

is not frightening to families... It's a very interesting learning process. As an English major in my past, it's been—the power of language is really interesting to me. That's how I would answer that. Oh, my God. We've been talking for an hour already.

Bryan Sisk: Isn't this fun?

Barbara Sourkes: Tell me what else you need to know. Yeah, I'm fine as long as—I have a long history to tell you about.

[00:51:43]

Bryan Sisk: One other area that I feel like has been under-addressed in this history of palliative care is education of the broader society outside of the hospital. What efforts, if any, have you seen related to that?

Barbara Sourkes: Not a lot. In the past whatever, 10, 15 years, there's a lot happening—more happening in the adult world, whether it's the death cafes, whether it's the letter-writing project. I have not seen a lot for the public consumer in pediatrics - and people just feel like this is such a remote issue or they're too frightened. It's something that concerns me a lot because it's part of what keeps the field and these families isolated. We have done some community talks in various venues when we've been asked, and even in a community agency that does grief counseling, but very little around children.

Even for them, it was very hard for them to listen, so finding a way is critical. I use children's drawings a lot when I speak and when I teach. Their images are very powerful and poignant, but they also have a lot of vitality. They're children! I have been stymied in terms of how to make this less overwhelming and more understandable to the general public—it's been enough of a challenge trying to make it understandable within a pediatric community. I'm not sure how... For example, when the IOM report came out, it published a summary brochure for the lay public. It was really well-written, it was really good, but I don't know how it got distributed. Whoever saw it, I don't know. I'd be interested in other people's ideas. I think it would be—in and of itself, I think it could be an interesting project to take on.

[00:54:04]

Bryan Sisk: We've talked about the adult hospice movement in adult palliative care and adult palliative medicine as this other track that preceded everything in pediatrics. How much did that adult movement affect both the spark of this development and then the longitudinal development of pediatric palliative care?

Barbara Sourkes: Pediatric palliative care initially came out of pediatrics, and soon after, there was a recognition that, oh, there's actually a field of

this, called this. in the adult world... People realized that there was a structure already. I don't remember the second part of your question.

[00:55:06]

Bryan Sisk:

How did it affect its development over time?

Barbara Sourkes:

I think mostly positively. Pediatrics is so small, it's important to know there's a wider world. That's been positive. The fact that there was a structure, whether we accepted it or not, but there was something to start with - I think the universality of the issues is clear. And it was a situation where everybody learns from everybody... Once we realized that the adult world was much more established, we had the benefit of learning what to do and what not to do.

I think the adult world has watched us also in terms of broadening their focus and wishing they weren't stuck with that "six months" clause. [Also, the adult world's initial exclusive focus in oncology and then HIV and recently a broadening to other disorders – they may be influenced by us.]

[Pediatric palliative care, in a way, has reached a certain maturity. In the beginning, we felt so completely subsumed by the adult world that it was really, really important to make our own statement.] But maybe now we've separated out maybe even more than we should, e.g. at palliative care meetings, at hospice meetings. It was initially so important to have our own venue and our own voice. However, it would be too bad if we become "two solitudes," - if we completely lose the fact that the universality of this human experience and the impact on families and the impact on us as providers is the commonality. It's a commonality, but how it's played out may look different...

One thing that came from the world of adult hospice that has been hard [is the belief that dying at home is the gold standard of care.] I don't think it's necessarily true for adults, and I really don't think it's true for kids. I think that was one of the core concepts in adult hospice—death either at home or in a palliative care unit -but the latter are rare for children.

That focus, that value, that zealousness about a "successful" death means dying at home was not helpful. It's taken a lot of time in pediatric palliative care to say it may not be right for some children and families. That was something we inherited to "undo," in a sense, to at least undo its universality...

[00:58:41]

Bryan Sisk: It struck me as we were talking about how pediatrics and adults developed over time, and pediatrics initially wanted so stringently to stand on its own, and then eventually, maybe—

Barbara Sourkes: Yes.

Bryan Sisk: It's describing the development of an adolescent. *[laughs]*

Barbara Sourkes: It is. That's a really good analogy. That's a great analogy. Yup. You've got it.

[00:59:04]

Bryan Sisk: We're in our 20s and getting into our 30s and we're thinking, maybe our parents are okay. *[laughs]*

Barbara Sourkes: Bryan, that's absolutely what I was saying. I just couldn't quite get the metaphor. That's absolutely perfect. It's true. It's so gratifying in ourselves when we watch our kids when they actually do return in a certain way. That's very funny. Yes, you do have to differentiate. You have to do that to establish yourself, and just not to go so far that there's no coming back. That's really interesting, yeah, for sure.

[00:59:41]

Bryan Sisk: Along this path, you wrote two pretty impactful books, "The Deepening Shade" and then "Armfuls of Time".³

Barbara Sourkes: Yeah.

Bryan Sisk: What was your big driver to take what you were doing and turn it into books?

Barbara Sourkes: Remember, I said I was an English major. I'm a writer by instinct. I love to write. There was very little written. That was my inner sense of how I could make an impact on the field, just it came from within. It didn't come from an academic requirement—that was a bonus. It came entirely from within. I just knew that I was seeing things in a certain way that had not been written about, and I wanted to do it. I wanted to teach it...

For the first book, when I was working on it, [the late Frederick Hetzel, then Director of the] University of Pittsburgh Press, became a very good friend. One day when I was visiting, I told him that I would soon be sending in my manuscript. He said, "The hardest thing—writers don't realize it—the hardest thing is a good title." I said somewhat smugly, "Oh, I have my title. I know what

³ Sourkes, B. (1996). *Armfuls of Time: The Psychological Experience of the Child with a Life-Threatening Illness*. University of Pittsburgh Press.

my title is." He looked surprised. He said, "What's your title?" I said, "From the Roethke poem, "In a Dark Time." My title is 'In a Dark Time.'"

He said, "If anyone else has used that title recently, you for sure can't, because your books will get mixed up. Let's look up *Books in Print* " This was a huge tome that came out every year or two. Can you imagine? I feel like a dinosaur. He goes through it and through it and through it, and he says, "You can't use it. A thriller just came out last year called *In a Dark Time* from the same poem." I was so crushed, Bryan. I'd loved this poem since undergrad. When I first read it, when I was 18, I said, "Someday, I'm gonna do something with this." I was very crushed. I knew he was right.

I went home, and I spent the weekend reading everything Roethke had ever written. Then I come back to that same poem and the opening line says, "In a dark time, the eye begins to see. I meet my shadow in the deepening shade." I said to myself: "you're such an idiot. The whole book says it's *not* all dark. It's not a dark place. It's a progressive light to dark, dark to light." That's how it became *The Deepening Shade*. [laughs] I'm very happy that it became that. That book really set my framework for my kind of work.

The Deepening Shade addressed issues that are universal - for children and adults. My complete love working with children, that's where the second book, *Armfuls of Time*, came from. I could have done a third one on siblings, but it's gonna be left for somebody else. I don't have it in me anymore. [laughs] The books came out of—that's just my way of expression. That's where they came from.

[01:03:10]

Bryan Sisk:

What was the reception after—especially for *Armfuls of Time*? Because there wasn't much published by the time that came out.

Barbara Sourkes:

Both were adopted a lot in hospital settings and in some coursework. [Some patients and families have read them – their responses (often expressed in heart-felt letters) have meant the world to me.] Neither became the popular press, obviously, given the topic, but they were both used a lot. They're still used a lot because they don't date. The late Jimmie Holland, who was Chair of Psychiatry at Sloan Kettering for many years, gave *The Deepening Shade* to every incoming fellow. It was like, "This is the guide to how you do psychotherapy."...They sold a fair number of books. I just can't tell you exactly. Certainly, they were also the springboard for any teaching I did and for speaking.

What I had learned was poured into the books, and then what I put in the books came back in terms of my teaching. One interesting thing—and I think it has to do with their emotional power — people mix up the titles for both books. For *Armfuls of Time*, I have heard things like: "I read your book, *Armfuls of Tears*," or "I read your book, *Armfuls of Sadness*." Then instead of *The Deepening Shade*, I've had *The Darkening Shade*. My publisher, laughed about this. He said, "They're very evocative titles, but they're very projective." The *Armful of Tears* has come back to me a lot. [laughs]

[01:05:03]

Bryan Sisk:

That's a hard thing to conceptualize. What do you do with a liquid in your arms? [laughs]

Barbara Sourkes:

Exactly. What do you do with the abstraction of time? The books were—that's my artistry. That's just where it came from. As you write them, you just pray that they'll actually get used.

[01:05:26]

Bryan Sisk:

For the last few questions, I want to just look broadly over your entire career, and then on the last question, look to the future. Over your career, what do you think have been the biggest care—biggest changes in the care that we provide for these kids that are suffering and dying from illnesses?

Barbara Sourkes:

Things I've witnessed?

[01:05:46]

Bryan Sisk:

Yeah. What do you consider the biggest changes from then until now?

Barbara Sourkes:

Pain and symptom management have to be the core of all care. That's been huge. I'd say the increasing focus on the child's voice, not only psychologically, but in terms of assent or consent, really listening for it and asking for it. Siblings - there's some increasing focus on them, a little better awareness of their experience. I don't think we're anywhere where we need to be, but it's beginning. I think one of the most interesting things has been the expansion of the spectrum of palliative care in the last five, six, seven years, to include the complex chronic population. I don't know, six, seven years ago, we wouldn't have had all those "complex chronic," in quotes, kids under palliative care. People would have said, "Why are they under that rubric?"

The language has gone along with the changes. When it all started, it was "terminally-ill" children. Who says that anymore? It went from terminal, and then it went to fatal, which people thought was a little broader, and then it went to life-limiting, and then it

broadened to life-threatening, and now it's broadened to chronic. That's been a huge change... It's been the broadening of the who comes under the spectrum.

I think that there's increasing recognition in hospitals that pediatric palliative care teams can play a very integrative role - among teams and between teams and families...

I think a big change has been around bereavement. The early definitions of the spectrum of both adult and pediatric palliative care always started at diagnosis and they ended at death. Bereavement wasn't even on the graphic. That's been a big change. If you're talking about comprehensive care, a child's death obviously is *the* significant marker, but bereavement has to be within the spectrum. It can't be a luxury item or an afterthought, which is how it was in the past. That's been important for funding - getting bereavement counseling covered as something very legitimate. I think there's much more awareness of that.

I also think there's more recognition and work being done around staff and trainee distress, really looking at, "how do we address their pain - how do we help people?"

And overall, the blossoming of the research is just unbelievable in the last 15 years, from almost nothing to really a pretty broad-based field. So I think there have been a lot of changes.

[01:09:04]

Bryan Sisk:

You've mentioned a couple of these, but what do you think are the areas where the field needs most to grow?

Barbara Sourkes:

Having different pediatric subspecialties understand us and understand how and why and when to refer, that's still a challenge with many. I think the debate about palliative care as its own specialty versus palliative care within specialty care is a question. What's the balance, and when do you want one or the other?

I have some concern about diminished interdisciplinary functioning in some teams. It's just so much the ethic and the value of this field. In addition, I am concerned that the more medicalized, the field becomes, it becomes hierarchical, which it didn't used to be.

Both concern me because the whole concept is about spokes in a wheel, right? We each contribute something. I don't want the field to lose that perspective because I think that has been such a rich part of the picture. I'm not saying it *has* lost it, but I think it's something that we have to be cautious and aware of.

We've got to be keeping an umbrella for everyone. I think we need to have much more community support, home care, respite care—respite care is huge. Much about the seamless transitions that we talk about and don't achieve frequently enough.

I've talked a lot about the need for optimal psychological care, recognition of its importance..

I think that the development of perinatal palliative care is exceedingly important...With all the genetic discoveries and new technologies, there are a lot of new issues coming up, Both in the immediate situation and then in the implications for families and future children.

I think we need more clinical trials to figure out, what are we doing that's effective? What do we think is effective, and what are we doing? What are some of the outcomes? I think that will be very, very important. Those are the things I think that lie ahead generally.

[01:11:49]

Bryan Sisk:

I have a tough question for you. What is your favorite or most lasting contribution you've made to the field?

Barbara Sourkes:

My books - not just the writing of them - but my commitment to a really deep understanding of these children and families and recognition most particularly of the child's voice. I know I've done that with individual families in my clinical work over the years, of course, but I would say my books - because they've become the expression of what I hope I've contributed to the field.

[01:12:34]

Bryan Sisk:

Then lastly, I'd really love for you to dream aloud. If all of the barriers that we talked about didn't exist, what would you ideally want the care of these children to look like in ten years?

Barbara Sourkes:

I would love it if there were more *early* referral for many different conditions. Understanding of the importance of early referral is a dream for enhancing our effectiveness. When it happens, it's amazing.

Respite care is probably almost the biggest need for families, so if there were truly funding for respite care at home or in freestanding facilities. That's a big dream. Truly more focus on siblings and on grandparents. I think grandparents get forgotten, and yet they're often taking care of two generations.

It's interesting you asked me earlier about public education because I had that in my notes, actually. More education of professionals and institutions that deal with children - schools, community centers, religious institutions, and the public. How can we convey that? I actually had that as a dream. I just don't have an answer for it. Much better funding. Making it less of a struggle, whether it's at an institutional or government level, including for bereavement. And continuing burgeoning research.

Bryan Sisk: Those are good dreams.

Barbara Sourkes: They're hopes and dreams.
[01:14:17]

Bryan Sisk: Yeah. Anything else from this history that you think I've missed or that you want to tell me about before we end?

Barbara Sourkes: I'm just looking at my notes. I think we went through that outline... I guess what I'd want to add [is the critical role of support for professionals, including trainees. We train professionals to care for these patients and families – but not how to take care of themselves– to acknowledge the impact on them]...

I think that there's an increasing recognition of this need.

Bryan... the residents come in now - and even though they may not have learned a lot about palliative care in medical school - they're not afraid of it, and they have a general sense of it. The residents say to us: "Every kid in this hospital should have a palliative care referral!" And I think - wow! Over 10 to 15 years, it's become a new culture. I think it's a very exciting and hopeful field.

[End of Audio]
