Biography

Joanne Wolfe, MD, MPH is the Division Chief of Pediatric Palliative Care at the Dana-Farber Cancer Institute, the Director of Pediatric Palliative Care at Boston’s Children’s Hospital, and a Professor of Pediatrics at Harvard Medical School. Dr. Wolfe has served in a multitude of local, regional, national, and international leadership roles and committees related to pediatric palliative care. She has participated and served as the PI research focused on easing suffering and enhancing wellbeing in seriously ill children and their families. Her early work identifying symptoms experienced by children in their last month of life raised awareness of the need for deeper study and better care in pediatric palliative care. Currently, Dr. Wolfe is serving as the president of the American Academy of Hospice and Palliative Medicine. Her appointment marks the first time a pediatrician has served in this role.

Interview Abstract

Dr. Joanne Wolfe begins the interview describing some transformative experiences as a trainee in her pediatric oncology fellowship that demonstrated a deficiency in the care provided for children and families managing chronic and complex illnesses.

Dr. Wolfe recalls several fortunate encounters of meeting like-minded people after enduring instances of resistance from colleagues and other providers for her early research work in end of life care for pediatric oncology. These serendipitous encounters led to many pivotal moments in her life, including publishing her fellowship research in *New England Journal of Medicine* and *Journal of the American Medical Association*, and eventually leading into a career of pediatric palliative care research and practice.

Dr. Wolfe describes many instances of growing and learning from mistakes in her research, and she reflects on the many fruitful partnerships that she has benefitted from in her career. In the future, Dr. Wolfe would like to see streamlined relationships within interdisciplinary teams to provide the best inpatient, outpatient, and home health care possible.
### Glossary of Acronyms

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<td>American Society of Clinical Oncology</td>
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<td>CHOP</td>
<td>Children’s Hospital of Philadelphia</td>
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<td>GI</td>
<td>Gastrointestinal</td>
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<td>Heme/onc</td>
<td>Hematology oncology</td>
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<td>ICU</td>
<td>Intensive Care Unit</td>
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<td>PACT</td>
<td>Pediatric Palliative and Comfort Care Team</td>
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<td>PediQUEST</td>
<td>Pediatric Quality of Life and Evaluation of Symptom Technology</td>
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**Edited for grammar and content by Dr. Wolfe. Additions and redactions indicated by brackets and ellipses, respectively.**
Today is September 20, 2019. I am Bryan Sisk and I'm in St. Louis, Missouri interviewing Dr. Joanne Wolfe over the telephone for Pediatric Palliative Care Oral History Project. Dr. Wolfe is in Boston, Massachusetts. Thank you Dr. Wolfe, for joining me today. To get us started, could you just tell me when your mind turned towards pediatric palliative care as a career focus.

Sure. It's nice to be chatting with you today Bryan. My interest in pediatric palliative care started in the mid-1990s when I was a pediatric oncology fellow. I had some sentinel clinical experiences both during my residency training and during my clinical year of fellowship, which suggested to me that there was some room for improvement in how we cared for children with advanced cancer.

At that stage, I was thinking about end-of-life care as opposed to the longitudinal care of children with advanced cancer. I also was at a place in my career where I was thinking about what to do for my research years of fellowship. I had never intended to be a basic scientist and there was an amazing investigator in the adult oncology at the Dana-Farber who was one of the people who started the field of outcomes research in cancer care, Dr. Jane Weeks. Jane became my primary research mentor as I tried to identify to focus on from a research perspective.

I'll just pause there for a second and say at the same time, a major study was published in the care of adults at the end-of-life who died in the hospital, the SUPPORT study. That study uncovered a lot of opportunity for improvement in the arenas of communication, advanced care planning, symptom management, and all other manner of care for adults at end of life.

of the publication coincided with both me thinking about my clinical experiences and talking to Jane Weeks, who wrote a few papers from the SUPPORT study. Together we decided that it would be great to look at the quality of care for children with cancer at end-of-life through the perspective of the bereaved parent.

We talked about doing a “quick and dirty” study in the sense that in the adult world you might be able to interview 100-500 patients facing end-of-life in a very short period of. In pediatrics, we decided that to accrue a sufficient sample we would begin by interviewing bereaved parents as a way to take a quick look at the quality of care that children were receiving at end of life.

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As it happened, it took about four years to complete the study to accrue a sample of 103 parents. While longer than expected, it was a personally very enriching experience and led to uncovering a lot of opportunity for improvement. It also led to some impactful publications and sort of jump started my career in pediatric palliative care.

I also had the opportunity to participate in a year-long collaborative that was run out of the Institute for Healthcare Improvement. Don Berwick, [head of IHI] and Joanne Lynn, who had been the PI (principal investigator) for the SUPPORT study, were running the collaborative. [Participating meant that you could go with a team to think about end-of-life quality improvement efforts for your institution.] The president of the Dana-Farber, knowing my interest decided to support me and three other interprofessional clinicians to [participate; we were the only pediatric team]. Over the course of that year we developed the Pediatric Advance Care Team, which began in 1997, the first pediatric palliative care service at Dana Farber Cancer Institute and Boston Children's Hospital.

So, both through my research and then through the collaborative, I started to focus my career on thinking of ways to improve the care of families of seriously ill children, first focusing on cancer and then beyond cancer.

[00:05:30]

**Bryan Sisk:**

So, early on when you were developing your research project as a fellow, were you envisioning a career a researcher? Or did you see research as a gateway to becoming a clinical leader in that field or both?

**Joanne Wolfe:**

I don't think I had a vision of what my career would look like beyond the next day, to be honest. It was a very organic experience as I hadn't been an investigator before I started my fellowship. I had published one paper in my chief residency, which was a case report. Actually, when I went to medical school and then residency, I had been on the primary care track and had wanted to be a general pediatrician. So, my interest kind of evolved as I discovered what it meant to be a doctor and what it meant to be a pediatrician. My interests evolved as I was exposed to different types of experiences.

So, as I think back, I couldn't say I had any plans for what I would do beyond fellowship. I think it may be very different now. It may also have something to do with my background, not coming from a physician-focused family, or a family that was academic in any way. It was just not something in my mindset.

[00:07:21]

**Bryan Sisk:**

You had talked about how there were some sentinel clinical experiences you had both in residency and fellowships. Are any of those really salient that come to mind that you would want to talk to me about?
Joanne Wolfe: Sure. Well, off the top of my head, three come to mind. The first was in residency, I was on call. At the time, the kind of oversight by attending physicians was pretty limited. I think increasingly over the years trainees are now more cared for and there’s a sense of them being in a developmental phase of life where you're not functioning independently. However, at that time, it was a sink or swim mentality I think, and you were often alone in the hospital at night.

I recall being either an intern or a junior resident—on call overnight for a child who was basically dying. The underlying cause, as I remember, was osteogenesis imperfecta and this child was extremely uncomfortable and there was no guidance provided to me, overnight, about how to care for this child.

I sat with the family. I adjusted some pain medicine, but I don't remember exactly what I did. In the end, the child died overnight. What was striking to me was more that the nursing staff said to me, "Oh, we're appreciative of what you did overnight, that you actually cared for this child." So, it seemed that what I had done was a little unusual. For me, personally, it was both meaningful and scary, and felt like I certainly would have benefited from more supervision and guidance.

Then fast track to when I was a senior resident. This story was written about in the New Yorker by Jerome Groopman who wrote about our pediatric palliative care program several years ago. I was the senior resident in the ICU [Intensive Care Unit], which meant that I was responsible for any critical situation that happened within the hospital. Typically you make your rounds, go to all the floors where there're sicker patients, check in with the resident and see whether or not there was anyone we needed to worry about.

Lo and behold, I came to the oncology unit and there was a very distressing situation of an adolescent boy who had been sent by his father with his older brothers to Boston from the Middle East to be cured of his cancer. He had widely metastatic disease and he was reaching end-of-life in high distress from dyspnea and pain, and there had been no decision making around resuscitation status, not for lack of trying I will say; it was the middle of the night and there was no plan.

I checked in with the junior oncology resident. The plan, as it was explained to me, was that they were going to do a “slow code” if the patient stopped breathing. My knowledge of ethics at the time was not great; however, that felt unethical to me. I ended up saying, "Oh, I see," and then went back to my call room. It happened to be that I was very pregnant at the time. My only thought was, "Gee, I hope nothing happens
on my watch." Right. So, it wasn't so much, I should figure this out. I was more just hoping I would get through the night.

Of course, as soon as I got back to my call room, it turns out that one of the brothers pressed the code button and I ended up running back to the floor. I was there with one of the NICU [Neonatal intensive care unit] fellows and two other residents. I remember exactly who was in the room at the time. We ended up kind of resuscitating this young man, with his brothers being highly distressed and expressing anger during the whole period. We ended up also calling the attending who came in from home, but we were sort of using bag valve mouth mask ventilation at the beside until the attending came in.

At that point, all agreed that he should be intubated and go to the ICU; now in retrospect, he should have been intubated much more quickly. He ended up being in the ICU for a few days and dying after a unsuccessful cardiac resuscitative effort. The whole thing created a lot of questions in my mind, a lot of distress. It was also so sad personally; one of the brothers, kind of cursed my unborn child, which was just a really unpleasant experience, not that I shared that with the brother at the time. It was just awful. It's just not the way things should be. So, that was yet another experience.

Then when I was a fellow, I had another situation with a poor child at the end-of-life with widely metastatic neuroblastoma and in excruciating pain. Again, there hadn't been anticipatory guidance about what the pain management plan was and how to escalate pain medications and all the stuff that we do now. That was just left to trial and error and depended on who was on call—that sort of thing. So, those are a few experiences that come to mind. I remember the names of these children. They're seared into your brain in ways that forever underscore why you do this and you're trying to affect change.

[00:14:24]

**Bryan Sisk:** So, as you were going through your heme/onc [hematology oncology] fellowship in the '97, '98, and you had teamed up Jane Weeks and you were doing this end-of-life study, were you aware of pediatric palliative care at that time? Or was that not something that was really front and center in your mind?

**Joanne Wolfe:** Well, we started our program in 1997 and I would say that there may have been one or two other programs that I was aware of in other institutions. But it wasn't like a community or an entity. The other community that I became integrated with, which was very helpful to me, was *The Project On Death in America*, Faculty Scholars Program, which I applied for was fortunate to have the opportunity to participate in. There are a lot of cute
serendipitous stories about why certain things happened early on in my career. Do you want to hear this story?

Bryan Sisk: That'll be great.

Joanne Wolfe: So, as I had told you during my fellowship, I was doing the data collection. At about 30 bereaved parents, I decided to submit an abstract to ASCO [American Society of Clinical Oncology]. My abstract showed that there was a lot of pain and distress in children with cancer at end-of-life. It was abstract that ended up turning into the New England Journal of Medicine article that I published in 2000.

However, it was just 30 parents at that time and my abstract was rejected. I was disappointed, and it turns out that anyone that Jane Weeks worked with usually had a plenary presentation for their abstracts and their first papers were in high profile journals; yet, here I was, with my rejected abstract. Not that I was competitive, but yes, it bothered me.

A couple months later I received an email notifying me that I had received an award from ASCO called the “Pain Merit Award” and it was for the best abstract that had to do with pain in pediatric patients with cancer. Well, it probably was only abstract that had to do with pain in pediatric that was ever submitted to ASCO.

So, then there was this very awkward situation where I received this really lovely award, but my abstract wasn't even going to be presented. So, as a good mentor should, Jane reached out the person who was in charge of the scientific program at ASCO and explained this conundrum and they, therefore, allowed me to make a poster for ASCO meeting; and, to be able to receive the award. So, mine was the only poster that had a number and then a little letter like “a” attached to it because they had already assigned all the numbers to the posters, so they had to fit me in between like 257 and 258, so I was 257a at that meeting. That lead to several other opportunities.

So, first of all, only three people came by my poster. One was the woman who headed up pediatric oncology at Children's Hospital of Philadelphia at the time. She looked at my poster and she said, “Well, now we know that the care at Boston Children's Hospital is poor at end-of-life for children with cancer,” because it was a single center study. So, she was like, “And we do better at our institution.” So, that was number one.

The second person was Joanne Hilden, who at the time was in Minneapolis, and she said, “I would love to collaborate and do the same study at my institution,” which is how I ended up doing a dual center study early in my fellowship.
The third person that came by was Jim Cleary, and it just goes to show you how meaningful these things are. At the time he was an oncologist and really sort of a big name in adult palliative care and has since been kind of one of those either guardian angels or sponsors, someone who, from a distance, kind of helps you in your career, so it was really meaningful that he came by. Now I try to also lean into these situations as a senior person, it is really important.

The second was, that I ended up being presented with this award right before Kathy Foley, I don't know if you know who she is, Kathy Foley was being presented with a lifetime achievement award by ASCO. So, she happened to be right there where I was presented my ASCO award for research in the care of children with cancer at end-of-life, especially as it pertained their pain and suffering. Then she was presented her big award.

But she came up to me afterwards and she said, "You're doing really interesting research. I don't know of other people in pediatrics who are doing this kind of research. Why don't you apply to the Project on Death in America? And, I'm going to invite you to give a talk at Memorial Slone Kettering."

So, the two additional things that came out of this rejected abstract were that I met Kathy Foley and I received my first national lecture invitation. [Kathy was the head of the whole Project on Death in America program and she was supportive of PDIA my application. So, I applied and was accepted and that became another career transforming experience.]

I met so many leaders in palliative care. There were a small number of pediatricians, but it gave me the opportunity to meet Diane Meier, and Sean Morrison, James Tulsky; all these folks, though earlier in their careers, were doing really important work in palliative care and they got to know me too. The grant also afforded protected time to do my work; at the time there were no grants to do pediatric palliative care research. We also participated in these retreats every summer where a very small group of folks came together to learn together and had mentorship and we had leadership training as well. In fact, Kathy Foley was the head of the larger program and Susan Block, who then later on in my career became my department chair, was the head of the training program. So, meeting her at the time was very meaningful as well. Now, I don't remember what the question was that you had asked me.

[00:22:16] **Bryan Sisk:**

It doesn't matter, this is phenomenal. [laughs] So, one thing I'm really interested in, you brought it up a little bit when the professor from CHOP [Children's Hospital of Philadelphia] came by and said, oh, this is what's happening at Boston Children's. How, as a young faculty, that
miraculously publishes in *New England Journal of Medicine* and in *JAMA* [Journal of the American Medical Association] the same year, both of which potentially could be viewed as "our institution is having this type of care," how was that viewed by your bosses at your institution?

**Joanne Wolfe:** Well, that's a great question. I was fortunate to have some very senior people who recognized the importance of this work despite the complexity of it showing that in a single institution that there was opportunity for improvement. Some of those folks were David Nathan, who was the Chief of Medicine at Boston Children's; I had served as the chief resident under him. He then became of the president of Dana Farber in the second half of the 1990s. Sam Lux, who was my division chief at Boston Children was also very supportive. Both of them are basic scientists and translational researchers, but they were able to appreciate that my focus on palliative care was important and novel, in the sense that it was a new area of focus for pediatric oncology, and they had my back in a sense.

Others were not as supportive. For example, the head of neuro-oncology at the time, was so upset about our publication that when it came to my next study, which was an intervention, the PediQUEST [Pediatric Quality of Life and Evaluation of Symptom Technology] study, to try and improve outcomes, he was reluctant to have patients participate, "So, it was bad enough that you publicized that our care isn't good quality, and now you're trying to get to our patients and whatever." He was not so supportive at that time.

Then, someone else in my division came up to me, passing me in the hallway, and said, "I can't believe you're focusing on this area of research, Joanne, it's academic suicide," and then she walked away. [laughs] It was like, a. who asked you, and b. you don't just tell someone that in the middle of the hallway. So, I had a lot of vulnerabilities.

I think I was also able, for whatever reason, perhaps because of my background of doing things a little outside the box to not concern myself with the laggards or the naysayers. I also probably always embraced this attitude, "Well, this is important. I hope it's successful. It's not going to be harmful, and if it doesn't work out, so be it. I'll give it my best effort." … So, yeah, there was some backlash.

[00:26:02]

I can also tell you a little funny story about how my paper got published in the *New England Journal of Medicine*, because that's another story that's a bit serendipitous.

[00:26:14]

**Bryan Sisk:** I would love that.
Joanne Wolfe: So, as I told you, Jane Weeks other mentees had published papers in high profile journals. When I finally had my manuscript I was talking to her about how I'd really like to submit it to the *New England Journal of Medicine* because I thought it was novel. She was like, "Single center, retrospective bereaved parent study, it's not going to cut it Joanne." I was disappointed and then sort of left the manuscript in her office, and we were going to continue talking about it.

It turns out that Bob Mayer—he probably doesn't even remember this - I should tell him this story because I work with him closely now. He was a very prominent adult oncologist, head of GI (Gastrointestinal) oncology, and he happened to be on the editorial board for *New England Journal of Medicine*.

Jane was meeting with Bob and at the end she said, "Well, I've been talking to my mentee, Joanne, pediatric oncology," he had no idea who I was, “about whether or not we should submit this article to New England Journal of Medicine.” He said, "Let me have a look at it."

She gives him the manuscript, and he happened to be walking over to an editorial board meeting at *New England Journal of Medicine*, and he brings it with him, and he shows it to Marcia Angell who was the editor-in-chief at the time. The next thing I know, I get a phone call from her office saying, "Is this your final submission? We would like to look at it." I'm like, "Oh my God. No, I think I'll send you a slightly updated version of it." But it was, yeah.

[B0:28:22]

Bryan Sisk: Wow. Well, that doesn't happen every day.

Joanne Wolfe: See isn't that a funny story. [laughs] Yeah. So, anyhow, that was about that paper. What were we talking about again?

[B0:28:36]

Bryan Sisk: I think we were about to move on. I love hearing stories of serendipity because I think it's so easy for people, especially as trainees at my level, to look at the Joanne Wolfes and the Jane Weeks', the Chris Feudtners, and the James Tulskys and say like, "Oh, well they must have had a plan from day one and everything worked out." In reality, it's hard work but it's also just the craziest happenstances that lead to some of these things. It's just amazing.

Joanne Wolfe: Yeah, however, I thought about this a lot First of all, it's leaning into a situation and a saying, "I think my work is important enough and I'm going to push this a little bit." Second, it’s about mentorship and sponsorship and having people just go to bat for you.
So, there's both, so yes, there's serendipity, absolutely. Had my rejected abstract not gotten an award, who knows if I would have gotten funding. At the same time, you have to learn about graceful self-promotion, and not be overly inhibited or shy about putting yourself out there, and also finding—you actually can actively find people who are at more senior positions to serve as mentors and sponsors.

I mean, who is it that I mentor? It's often people who come to me who say I'm interested in your work and I'd like to hear a little about—and can I tell you what I'm doing. Then the next thing you know, we're meeting on a weekly basis about their work. It's not because I said, "I'm going out to look for mentees." It's people who actually take initiative, present themselves and also recognize opportunities, that's really important as well; yes, there is also a lot of serendipity.

**Bryan Sisk:** Fate favors a prepared mind, but you have to have the prepared mind.

**Joanne Wolfe:** Exactly.

**Bryan Sisk:** So, thinking more about the clinical reality at that time—when you were starting out in the late 90s and you had started a palliative care service at Boston Children's, what were the biggest challenges in caring for children that were suffering serious illnesses?

**Joanne Wolfe:** So, I would say, there were enormous challenges. I would just say that one of things was really critically important was that we were a team. I've mentioned that. We had gone to this IHI collaborative.

I went with Janet Duncan, who was a nurse at the time, became nurse practitioner, and really sort of became the clinical expert in pediatric palliative care, as far as I'm concerned. The go to person on our team, both communication, and symptom management and a presence—her role-modeling was amazing.

Joanna Breyer, who's a psychologist and then Michael Comeau who—Michael was an outpatient nurse in the Jimmy Fund clinic. We worked together in strong partnership to build this program and so despite the challenges and sort of, yes, the challenges, it was amazing to be together and to sort of have each other’s back and support one another during this time.

I have this little slide show presentation—have you ever seen it about the 12 lessons learned in developing the program?

**Bryan Sisk:** No, I haven't.
Joanne Wolfe: I mean I could send it to you rather than go through it in detail. But we made numerous mistakes and just think about a few. Well, we started off small, which was a good thing to do.

We started off as a demonstration project in pediatric oncology. However, we didn't know what we were doing, right. So, one of the biggest mistakes we made was we had decided at first that we a consult team to clinicians and not families, and that's kind of what we did for the first little while. We decided to develop a brochure about how we can just—I don't know, it was mostly a team brochure. The language of that brochure was so insulting our constituencies; how providers don't always recognize when it's time to think about and talk about like the end-of-life care and how we could be supportive in that way. But it was just like really kind of, we didn't know that it would have been better to just sort of develop our approach through partnership and through a gentle sort of diplomatic way.

 Thankfully, despite our mistakes, we learned quickly how to be very collaborative and deferential to primary teams as opposed to sort of maintaining that "holier than thou" mentality, which is what led many palliative care services to be unsuccessful earlier on. But then the barrier was related to how we presented ourselves in the beginning, which was that palliative care was all about end-of-life care. We gradually learned and tried to sort of transform the message to one of early integration.

Again, it was really about seeing that this is not focused on end-of-life care but rather an added layer of support along the illness continuum. Those were words or concepts we had early on about what this was all about evolved organically learning, from our mistakes and learning that we just can't show up at the eleventh hour in order to affect change, if that's what you're trying to do. We definitely were seen, very early on, as the grim reapers once we started seeing patients.

I remember this one experience where we showed up on one of the general floors. There was a patient who we were invited to meet, and we sort of walk towards his room. The nurse stood in front of the room and said, "What are you doing seeing this patient? He's a healthy kid." As it happened, he was a healthy kid with maybe an asthma attack, and it turns up there were two patients with the same name on the same floor.

She was right [laughs], but we also felt her reaction was like even stepping into the room would make this kid sick. Gradually as we transformed our message and the way in which pediatric palliative care was perceived, and the way people saw us providing added value over time, then 10 years passed by and the way in which we were perceived was very much more as a welcome added layer of support. But there're so many ways in which we could have done things differently.
Another early intervention was that we held monthly educational sessions, which, to this day, we call PACT [Pediatric Advance Care Team] rounds. It created a forum for dialogue and around palliative and end-of-life care in our institution, and we never had that kind of a forum.

Every year at one of our monthly sessions, we invite a family to come reflect with us on what went well and what could be improved upon. We usually knew the families well, but for some reason we got the recommendation of a family of a child who had died in stem cell transplant unit. The father, in this case, talked with very high regard about the general oncology service and was very angry and negative about the stem cell transplant experience that his son had. Essentially, from that moment on, we didn't get a stem cell transplant consult for, I guess, about 10 years. With the public humiliation, was completely wrong on our part. We learned then we have to vet what the messaging was going to be. Then it turned out with change of leadership and time passing with stem cell transplant, there were new opportunities to become involved. There are several other mistakes and challenges that we face, and I'm happy to share that PowerPoint with you if you want to hear more about that.

Absolutely, that would be great. Thinking back on your career so far, what do you think personally were the biggest challenges as you were trying to launch this new direction at a big established institution?

I mean it's a little bit conflated and I have to say, Bryan, with my greatest challenge was as a mother and building a career in general, and having, over time, three small children at home and a husband who was also in academic medicine. So, it's a little bit hard to answer that question because there were numerous challenges just in general, I will say.

I do recall in the early days, now that we're talking about it, of being the only person who took call on our service and being in the park on a summer weekend with my kids, actually it was like a swimming/pool park, trying to support a hospice team managing a child who was dying at home, answering questions by phone and trying to keep my kids from drowning at the same time.

Trying to be available, especially when it was critically important to be available, and yet being present as a parent, that was hard. I will tell you that I learned early on, because of my sort of priority of being a mother, that I wasn't necessarily going to get a babysitter for that weekend so that I could be at the bedside of that patient. I always had this very compelling desire to be with my children and be very present and so I sort of figured out strategies that allowed me to do both.
But it was emotionally exhausting. I was also the case that when we were building this service were getting busy, I happened to also get a research grant and I was ending up spending more and more time doing clinical work even though I was supposed to be 75 percent protected for my my effort. I was again able to go to my boss, Sam Lux, and say "this isn’t right. I’m doing this clinical work and I’m also supposed to be doing research." And they finally allowed me to hire a fulltime palliative care physician to actually be on service, and I would be on service, two months a year, and she would be on service 10 months a year, and that's kind of how it transitioned from me being a full time clinical palliative care and trying to build a research program.

Bryan Sisk: So, then, when you finished your heme/onc fellowship, did you ever practice hematology or oncology? Or did you go directly to palliative care?

Joanne Wolfe: I practiced oncology many, many years. It was always like on paper, maybe 20 percent oncology and 10 to 20 percent palliative care, which then evolved over time. At one point, I was 50 percent clinical, and 50 percent research, it sort of fluctuated. Then we ended up losing a physician on our palliative care service, and so I took some time off from oncology which was only supposed to be a year or two and I never went back. I think I was kind of not willing to accept that for a while because I really love oncology.

But my role in oncology evolved from—I always had my own primary patients, especially patients who I had cared for during fellowship and continued to care for over the years and many of whom had more advanced stage of disease. I then served as a primary oncology attending for a while where I would supervise fellows. I worked together with them. I did some hematology for a while and I did oncology. Then for sort of the latter part, I stopped taking primary patients, but I would do new workups of children presenting with cancer. I stopped doing oncology in 2012.

Bryan Sisk: Just a few years.

Joanne Wolfe: Yeah, it's not so bad, seven years ago. Yeah.

Bryan Sisk: Thinking a little more globally, looking at kind of the field but also the philosophy of pediatric palliative care, what do you think really served as the spark in that development, historically, over the last 10, 20, 30 years? What do you think it was that really drove that to become a field?

Joanne Wolfe: I think that it was multifactorial. First of all, it was happening in parallel with was going on in the adult hospice and palliative care movement. So, we were developing at the same time. Several of us came to develop
pediatric palliative care hospital-based programs around the same time. Another early leader was Tammy Kang, who was at Children's Hospital Philadelphia and worked together with Chris Feudtner. He always was sort of the research person and Tammy was the one who developed the clinical side of the program.

Oh yes, Seattle was a very early program with Ross Hayes for example. Then Sarah Friebert at Akron Children's. There was a small number of us who were developing these programs. And early on, a small number of us decided to develop fellowship programs. I think Children's Hospital Philadelphia and we had that idea around the same time—of course this was before the match—but we recognized that we wanted to train the next generation of folks.

I think, Jenny Mack might have been our first fellow. And Christine Ullrich who's still with our program was a fellow with us. At first, when Christine and Jenny did it, it was integrated into their heme/onc fellowship, and then we finally got a grant from The Project on Death in America, actually to fund our first physician spot.

In any case—we then developed an intra-professional fellowship program, which has been in existence for a while too… A big transformation was having hospice and palliative medicine become a formal subspecialty, which happened in 2006, that's when it was. I think, the first board was 2008, but the sort of planning for that started in 2006. Yeah, that was when I think the grandfathering period started. That allowed more people to see it as a formal subspecialty.

So, I don't know, maybe I'm getting tired, and maybe I'm not answering your questions. But I feel like the reason why there was momentum was that we were doing it in conjunction with how the field was unfolding on the adult side.

[B00:48:12]

**Bryan Sisk:** When you look over your career from, in '97 when you started your program until now, what do you think are the biggest changes in the care that we can provide for these kids that are now suffering from serious illness?

**Joanne Wolfe:** Well, certainly there's much more widespread availability of subspecialty palliative care for children with serious illness. I think that there are emerging data suggesting that the involvement palliative care services improve perhaps a symptom distress, communication, results in earlier advanced care planning and end-of-life decision making. So, just by virtue of the fact that more and more of the services are growing and there's more integration.
Not every subspecialty has had the need to prove that they make a difference through randomized controlled trials; however, we're still aiming to show that, and certainly we've seen that on the adult side, that palliative care improves outcomes. At the same time, I think because of the existence of the field, there's more opportunity for training and research that's happening across subspecialties that care for seriously ill children. And just the quality of care that can be delivered at that generalist or primary palliative care level has improved because we have a field now. Because there are folks that are leading and also partnering with subspecialists from other areas to raise the bar across the care continuum for seriously ill children. The experiences of these children and families are improved and yet I still feel like we have a long way to go to make even more substantial improvements in their life experiences.

Bryan Sisk:

When you think about all of the different things you contributed to this field, your phase earlier was “graceful self-promotion.” What would you say is your favorite contribution that you've made?

Joanne Wolfe:

I hope that what I have facilitated in my work is serving as both a role model, a sponsor, and a mentor to validate this area as an important area of care and attracting very talented people into the field. I am confident, at this stage of my career, that we have incredible next generation of folks who are going to push things forward in an even more impactful way. I just hope that I contributed to that momentum of ensuring that pediatric palliative care is an incredibly important meaningful career path, whether you do it as a subspecialist or you integrate into your career as a clinician and/or investigator or educator in some way, so that we're not complacent and we realize that given the fact that there increasing numbers of seriously ill children that we're always looking for better ways to enhance their wellbeing and their family's wellbeing.

Bryan Sisk:

And then lastly, I really want you to dream aloud for me and think about 10 years down the road, if there were no budget or political or any other barriers, what would ideally see care for the children look like in 10 years?

Joanne Wolfe:

I think that there ought to be a continued growth of subspecialty pediatric palliative care in all sort of care settings. I still feel that for the most part, our programs are understaffed and not only in the clinical domain, but from an educational and research domain, because there's so much more to uncover and to teach. I'd like to see that the subspecialist in the field, again, are partnering even more intensively so that in these various setting, there is a culture of caring that’s proactive and very anticipatory, rather than being reactive, which is still where we're at in many ways, despite the efforts that are ongoing—so
that the experiences of these children and families are as good as possible given that they're sort of facing deep tragedies and loss. So, I just want this to continue to unfold in a way that there is partnership that exists for patients and families in the inpatient and outpatient and home settings.

[00:54:26]

Bryan Sisk: Well, those were all the questions I had. Is there anything else you think I should know about or should dig into in the future that we didn't hit today?

Joanne Wolfe: Oh no, I’m tired. I’m tuckered out Bryan.

[End of Audio]