Biography
Dr. Danai Papadatou, Ph.D., is the Director of Laboratory on Psychopathology & Neuropsychology at the National and Kapodistrian University of Athens, a Professor of Clinical Psychology as well as Professor of Nursing at the National and Kapodistrian University of Athens. Dr. Papadatou received bachelor’s and Master’s degrees in Clinical Psychology from the University of Geneva, Switzerland, a Master’s degree in Family Counseling & Guidance from University of Arizona, and her Ph.D. in Counseling Psychology from the University of Arizona.

Dr. Papadatou has been active in the pediatric palliative field for over three decades and has grown the field through her published books - Life losses- Bridges of Support, In the face of death, Introduction to Psychology for health care provider - 28 textbooks chapters, over 70 journal articles, participation in conferences and symposia, and community capacity-building projects. Her research includes examining health care provider and caregiver attitudes towards death and dying of children, psycho-social stressors of children experiencing natural disaster or crisis, and the examination of pediatric palliative home care practices. Dr. Papadatou is a founding member of the MERIMNA Society for the Care for Children and Families Facing Illness. She has also served in leadership and consulting roles for Association on Bereavement, the Greek Society for Pediatric Palliative Care, and multiple journals including Cancer Nursing, Mortality, Illness, Crisis, and Loss, Journal of Palliative Care, European Journal of Palliative Care, Psychological Issues, and Child and Adolescent: Mental Health and Psychopathology.

Dr. Papadatou was the recipient of the (2017) Aliki Giotopoulou-Maragopoulou Award for the valuable contribution to the support of bereaved children, families, and communities from the League for Women’s Rights, Greece, (2012) Award for outstanding university teaching, research, publication, and professional service in the field of dying, death and bereavement from the Robert Fulton Center for Death Education and Bioethics at the University of Wisconsin, and the (1989) Award for outstanding contribution to the world of hospice support for children from Children’s Hospice International.

Interview Abstract
Dr. Papadatou introduces her early beginnings in the field of pediatric palliative care and recalls several of influential figures in her life. These figures were “models of professionalism and humanity,” and included her father, her professor, and a 30-year-old woman with ovarian cancer who “made it a point to teach [physicians], advocate [for patients], and prove wrong all the prognostics.” Dr. Papadatou describes her international work in research, education, and her experience with organizing international events that incorporated some of the fields pioneers, such as Charles Corr, Elisabeth Kübler-Ross, Earl Grollman, Ida Martinson, Betty Davies, and many others. Dr. Papadatou then describes her work with seriously ill children in conjunction with the oncology department of her home hospital, as well as her research and policy contributions. She concludes with her perspective on how the field of pediatric palliative care can advance through a movement of interdisciplinary collaboration, communication, and planning.
# Glossary of Acronyms

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<td>ICU</td>
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Bryan Sisk: Today is June 25, 2019. I am Bryan Sisk, and I'm in St. Louis, Missouri interviewing Dr. Danai Papadatou over the telephone for the pediatric palliative care oral history project. Dr. Papadatou is in Athens, Greece. Thank you, Dr. Papadatou for joining me today. To get us started, could you just tell me when your mind turned toward pediatric palliative care and caring for children suffering from serious illness as your career focus?

Danai Papadatou: Well, there was an interest when I was a psychology student. I volunteered my services over the summer holidays in one of the largest pediatric hospital in Athens supporting seriously ill children. I realized back then that I felt at ease to play with them, to relate, to be around them. Even when they were at the very end of their lives.

I have to say that I was greatly influenced by my father, Costas Papadatos, who was a professor of pediatrics at the medical school of the University of Athens and a director of a university pediatric department in that hospital. Thanks to him I had also the possibility to travel to Sweden, and spend a summer volunteering my services in a play therapy department at the Karolinska Hospital in Stockholm. So, I became acquainted with creative ways of working with seriously ill children.

My scientific interest in pediatric palliative care started in 1981, when I decided to do a PhD at the University of Arizona and study the families of children with cancer. I came back to Greece to collect the data from a pediatric oncology unit, which was just opening at the children's hospital. While I was collecting data, I was also volunteering my services and when I completed my PhD, I was hired as a psychologist to work in that pediatric oncology unit.

That was at the very, very beginning. My career started in pediatric oncology where I worked as a psychologist. Then later on, I moved on to the university, obtained a position as an assistant, associate, and then, full professor at the school of nursing of the National and Kapodistrian University of Athens. This gave me the opportunity to introduce many topics and courses on palliative care and pediatric palliative care in the undergraduate and postgraduate nursing curricula

Bryan Sisk: In 1981, you came all the way to Arizona to do your PhD focusing on children with cancer.

Danai Papadatou: Yeah, I was already there since
Bryan Sisk: Oh, I'm sorry. Go on.

Danai Papadatou: I was already there since '78. I did a second master in Arizona and then proceeded with a PhD. Yes, I was very much affected by some people in Arizona who were very influential in my involvement in pediatric palliative care.

Bryan Sisk: Who was that?

Danai Papadatou: One of them was my professor of psychology, Bob Wrenn, who at that time was teaching a very popular course on campus, which was entitled “On Death and Dying”. He was very inspiring. Very open to address issues related to death and dying. And at the same time, very humble and very caring. Many times he invited into the classroom people with life-threatening illnesses and professionals who supported patients and families or even Indians who shared the rites of passage in death situations. Bob Wrenn was a very influential person in my choice to pursue a path in palliative care.

Bryan Sisk: When you were starting out, this was pretty early on.

Danai Papadatou: Yes.

Bryan Sisk: At least in the literature, there weren't a lot of people focusing on children dying, needs of families.

Danai Papadatou: No. Not, at all.

Bryan Sisk: Were you able to find, outside of Bob Wrenn, were you able to find other like-minded people?

Danai Papadatou: Yeah, at that time, in Arizona, there were two more people who were very influential to me. Fran Farrell, who was a nurse and social worker who was working with Professor John Hutter, at the pediatric oncology department of the medical school of the University of Arizona. She was extraordinary.

I followed her around in all her encounters with children and parents. To tell you the truth, I wanted to become like her. [Laughs] Wise, caring, humane. She and John Hutter had a very unique approach to support children, families, and their families from the very first moment of diagnosis. They invited all members of their support system and worked with the entire network from day one. These were new ideas and new approaches back then.
Another person who was also extremely influential to me was Melanie Robbins. She was a 30-year-old woman with ovarian cancer. Full of life, who became my very best friend. We were like sisters. She was bright, outspoken, social, with humor, and she had a goal to teach physicians and nurses how to respect patients. Melanie taught me how to make the most of every day, and how to face adversity in a positive way. She also helped me acknowledge the power that some patients have to sensitize and to teach professionals. Sometimes we think it’s the other way around.

Melanie made it a point to teach, advocate for the patients’ rights, and prove wrong all the prognostics. She made a difference in her own life, but also in the lives of professionals who were treating people with cancer. Yeah, I had models around me. Models of professionalism and humanity: Above all, my dad, of course, who was a pediatrician.

*Bryan Sisk:* Yeah, how did growing up as the daughter of a pediatrician affect your views and your trajectory?

*Danai Papadatou:* Tremendously. Because, first of all, the pediatric hospital was my second home. I felt at ease going in and out. I saw how caring he was with children. His private office was full of drawings and paintings from his patients, and they loved him. Parents, too. I learned from and through him.

I also observed how he collaborated with his interns and with other colleagues. He was a model for me of humility – of being authentic, caring. One thing he taught me was not to be afraid to be intimate in relationships with others. Sometimes being challenged by them both as a professional and as a human being.

*Bryan Sisk:* You had mentioned that Melanie Robbins, that one of her goals was to teach clinicians how to respect patients.

*Danai Papadatou:* Yeah, amazing.

*Bryan Sisk:* What was the standard? What was going on that were problems at that time that she felt needed to be addressed?

*Danai Papadatou:* Well, care was very medically oriented. Clinicians imposed decision. Melanie always negotiated with physicians. She would tell them; “I need to learn all about side effects. I need to learn more about the treatment you’re proposing. I need two days before I decide.” “Yeah, I need time before I decide. It’s my life.” I remember one time—can I share an anecdote?
Bryan Sisk: Yeah, absolutely.

Danai Papadatou: Yeah. I remember one time I was in the room with her; by the way, most of the time, she was in the hospital where I visited her daily. I remember her physician came into the room with all the interns, stood over her bed, and said, “Listen. Melanie, I have some sad news. Your cancer reappeared. We need to think of another treatment.”

Melanie said to him, “Well, do you know what I need most right now? I want you to sit down on my bed, just here next to me, and give me a hug. Tomorrow, you can come back, and we can discuss about treatments.” It was impressive that this big guy who felt so awkward, with interns giggling around him, sat down, and gave her a huge hug. When he left the room, [laughs] she turned to me, and she said, “See, they are learning.”

[Laughter] After her death, her physician attended her funeral. It was the first funeral he ever attended. I have to add something to this. 10 years later, I was back in Arizona visiting one of my professors. His wife had just died from cancer. We had just met, when he had to answer the phone. After the call was over, he said to me, “It was Joanne's physician who called to ask how I was doing after the death of my wife.” I was impressed. I then asked him, “Who's that physician who calls up on the family of the patient?”

My professor said, “Yeah, well, he was a very supportive clinician. And at the very end of Joanne's life, he gave us a choice to continue with treatment or to go home and introduce a palliative care team. We opted for the palliative care team. But this physician said, 'I'll be there for you if you change your mind, or for whatever you need.' We left. Before leaving, he gave Joanne a huge hug.” I again asked, “Who was that physician?” It was Melanie's.

Bryan Sisk: Wow. The things we can learn from patients.

Danai Papadatou: Yeah. If we are open.

Bryan Sisk: Yeah.

Danai Papadatou: If we see our role as offering something, but also receiving much more, if we allow ourselves to recognize the gifts the patients and their families bring into our lives.
Bryan Sisk: What was it that initially drew you from Greece to Arizona? It seems like not the biggest state in the country. [Laughter] What drew you there?

Danai Papadatou: That's true. There was no psychology department at the University of Athens in 1973. I went the first five years in Switzerland at the University of Geneva and did my undergraduate and graduate studies in Clinical Psychology. Then, met in Europe Professor Oscar Christensen, who was an expert in Adlerian family counseling at the University of Arizona, and wanted to learn from him.

I came to Arizona. Obtained a second master's degree, and then, pursued my studies by doing a PhD and a thesis on the “psycho-social factors related to the onset of childhood cancer”. Came back to Greece, collected the data, and went back to Arizona to support my PhD thesis.

Bryan Sisk: Outside of that close-knit group in Arizona, were you aware of other people around the country or around the world that were interested in similar topics?

Danai Papadatou: Yeah, I was reading anything I could get on my hands when I was a student. Then, in '89, when I was back in my country, along with my dad, we decided to organize the first international conference on children and death in Athens. All the professionals that I was reading about who were in the field of pediatric palliative care at that time, as well as in the field of bereavement, were invited at this first international conference.

They came from 24 countries, if I remember correctly. It was a huge success. From there, we also published one of the first books, Charles Corr had already published some books on pediatric palliative care, but we published with my dad, Children and Death, which contains some of the presentations that were addressed at that meeting in Greece. That—

Bryan Sisk: I've got it sitting right in front of me. [Laughs]

Danai Papadatou: Oh yeah? [Laughs]

Bryan Sisk: Yeah.

Danai Papadatou: Yeah, that would be—
Bryan Sisk: What I'm really interested in is what was the impetus? What was the big driver for you to work with your dad to develop this international congress?

Danai Papadatou: Well, because all the people who worked in pediatric palliative care and childhood bereavement, by the way, I was also interested in childhood bereavement, were isolated. There were no conferences. There were no meeting places. Along with my professor, Bob Wrenn and my dad, we said, “Let's do something. Bring them together. Let's do it in Greece.” My dad had a lot of experience in organizing international conferences.

Then, Bob Wrenn said, “Okay. You should consult Charles Corr, who is more knowledgeable about who is doing what.” I corresponded with Chuck Corr, and he helped me a lot to get in touch with professionals from around the world, because I didn't want to only include people from the United States. Yeah, and it worked out fine.

We invited Elizabeth Kübler-Ross, Earl Grollman. We had, of course, clinicians from Arizona, such as John Hutter, and Fran Farrell. Ida Martinson, who at that time was doing innovative work in the United States, and developed the first pediatric palliative home care program for children with cancer in Minnesota, [Betty Davies from Canada who was conducting research with Ida. Yeah, and many, many others including Dora Black, Hannelore Wass, Mooli, Lahad, Stephen Fleming, Sandra Bertman, Chuck Corr, Ann Armstrong Daily, Marcia Lattanzi).] (Added by Dr. Papadatou during review)

From that meeting then, I realized that there was a group of professionals who were meeting already every two years: the international workgroup on death, dying, and bereavement. It was an organization for those who were in palliative and bereavement care, who worked with both adults and children. Shortly after I became a member and joined them and still attend each meeting.

The international workgroup was a big support to me, because in Greece, when I started working in pediatric oncology, I didn't have anybody else who was familiar with the field. — I was introducing pediatric palliative care. Luckily, the chief oncologist, Helen Kosmides was very open to fresh ideas, to interdisciplinary teamwork, and things like that.
The group, my team of professionals that I could rely upon included members of the international workgroup on death, dying, and bereavement. We met regularly, every other year.

*Bryan Sisk:* I'm really interested. When you were planning this first conference on children and death in Greece, were you known in the field at that time? Was this—

*Danai Papadatou:* No. [Laughs]

*Bryan Sisk:* - fairly audacious of you to be the person organizing it?

*Danai Papadatou:* Yeah.

*Bryan Sisk:* What was that like?

*Danai Papadatou:* No, I was not known in the field. I have to say that because—of my work in the pediatric oncology unit, our team presented various papers at different European and international conferences. There was some attention on the kind of work we were doing back then.

Yeah, it was *Nursing Times*, journal that sent one professional photographer to see what we were doing in Athens, Greece in the oncology department, and later published an article on the psychosocial work with seriously ill and dying children.1 Yeah, there was some attention, but I was not known back then.

*Bryan Sisk:* Where did you get the confidence that you could succeed in pulling this thing together?

*Danai Papadatou:* Well, [chuckles] I had parents who believed in me, and encouraged me. My dad always encouraged me to present some of my ideas at conferences. The other thing was my mother who was an expert in organizing conferences. For me, it was like, “We can do it.” My dad, who was very well-known in Greece, had the possibility to raise the funds. At that time, the minister of education was one of his best friends, who opened and attended the conference. Yeah. We did it, and it was huge success. Beyond expectation.

*Bryan Sisk:* What do you think were the best outcomes of it? What showed you that it was successful?

*Danai Papadatou:* Usually when you go to a conference, especially in countries that are attractive or exotic, [laughs] nobody’s in the main rooms

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because they visit the country. The rooms were constantly full. While the speakers were not known to the Greeks, there were many Greeks and people from other countries who came to listen to these presenters.

We had, I think, if I remember correctly, 21 invited speakers from all over the world. There was rich exchange and interaction. Yeah, I think there was an interest at that time to learn from each other, because all these professionals were very isolated despite the fact that they were doing fantastic work. They were isolated in their own country. This conference was “the” opportunity.

It was a time that the first books were appearing on pediatric palliative care. Chuck Corr published the very first ones. Myra Bluebond-Langner, wrote a book on—the private world of dying children. Ida Martinson published her seminal research study on providing palliative care at home for children with cancer. Yeah, it was—yep.

_Bryan Sisk:_ One thing that stuck out to me while I was reading through *Children and Death*¹, the book that you and your father had edited, was the section or the chapter you wrote on the young Greek psychologist who you call Lito.

_Danai Papadatou:_ Yeah.

_Bryan Sisk:_ Who ends up being you.

_Danai Papadatou:_ Yes.

_Bryan Sisk:_ You talk a lot about burnout, and poor team dynamics, and a lot of the struggle.

_Danai Papadatou:_ Yes.

_Bryan Sisk:_ Could you talk a little bit more about that?

_Danai Papadatou:_ Yeah, my interest in how palliative care affects professionals was always the center of my concern. I was not afraid to be open about how it affected me. I was always very observant of team dynamics. I tried, in my own oncology team, to advocate for supervision, but there was tremendous resistance. It was few years later that I met with Ida Martinson again somewhere in Arizona, and we decided to undertake a transcultural study on how nurses and physicians are affected by the care of dying children.

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We conducted in Hong Kong and Greece a big study. Through the study, we developed a model on the grieving process of professionals who care about dying children in an ICU, in oncology, in neonatal units. This model was further developed and presented more comprehensively in another book I published many years later In the Face of Death: Professionals Who Care for the Dying and the Bereaved, 2009, by Springer.

Yeah, I always had a special interest. It is still alive, because I think we speak very briefly, or very superficially about how this kind of work affects us, and how it affects team dynamics, and team evolution. Sometimes we are unaware that it has a profound impact on all of us. In our personal lives and in our professional lives.

I want to bring this out in the open many times. Speak about it at conferences or introduce such topics in various courses, and sensitize those who support children to look into themselves. Otherwise, we cannot work effectively as a team if we don't know where we stand personally. It would be very difficult to work effectively in a team that is unaware of its deeper dynamics.

**Bryan Sisk:** When you were beginning your work, what else were the biggest challenges in providing this care and starting this field in your country?

**Danai Papadatou:** Well, at that time, even though we adopted a holistic approach at the oncology department, the biggest challenge was caring for children close to the end of their lives. At that time, most of the children with cancer were dying. Three out of four were dying. Only one survived. Which is not the case today.

Then, they wanted to return back home. Children that were treated in our unit, came from all over the country. These children and their families wanted to return home when death became imminent. There was no home care program at that time. We sent them home on their own, and kept a connection through the phone, or connected with local pediatricians, wherever there were available pediatricians.

These families were left on their own to care for a dying child. We decide to conduct a study, a feasibility study, and explore the experiences of these families who had a child dying of cancer. One

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of the main results was a clear preference for home care: “Yes, we want to be at home. Yes, we want professionals to be around to help us through this process.” Home is desired but also creates a lot of anxiety for parents who are left on their own to care for a dying child.

After this feasibility study¹ (1996), I decided to offer a training program in pediatric palliative care through the University of Athens (1997). It was in the early '90s. I was already teaching at the university. A training of 700 hours on pediatric palliative home care was attended by nurses, pediatricians, social workers, and psychologists. I also invited Ida Martinson to come back to Greece and teach pediatric palliative care.²

Anyway, it was a very successful program, because after that, we went to the ministry of health, and told them, “Here are the results of the feasibility study. Here are the hospital and community staff members who are trained for home care. Let's start providing home care.” The response was, “Oh, they're going to die anyway. Physicians and nurses cannot get out of the hospital. This is a matter for volunteers.”

I gave them the book on “children and death”. I tried to educate them and sensitize them on the need for pediatric palliative home care, but I found a wall. Then, decided to create a non-profit organization that would provide pediatric palliative care and childhood bereavement support to children in need here in Greece. That's how “Merimna”, which is our non-profit organization was founded in 1995.

**Bryan Sisk:** Now, is home care and palliative care in Greece still primarily driven by philanthropy and donations?

**Danai Papadatou:** Yes. Merimna is the only non-profit organization that provides pediatric palliative home care. We started with childhood bereavement services because there was stigma associated with dying children at that time. Then, progressively moved into pediatric palliative home care. We are the only program right now in Greece, which addresses the needs of a limited number of children, and depend on private funding.

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The most optimistic aspect is that over the past year, a national committee for the development of palliative care in Greece that was created by the ministry of health. We just completed a feasibility study. This national committee is moving forward to develop a strategic plan for introducing palliative care in Greece. There is hope that things will change.

What we provide through “Merimna” is very limited to approximately 25 children per year. Even though we are in contact with all the pediatric hospitals of Athens and collaborate with all the units that care for seriously ill children, we cannot cover a great number of children. We are limited to those living in the area of Athens. We need to expand. I hope the government will proceed with the new legislation and offer new possibilities for developing palliative care for both adults and for children. We are the advocates for children’s right.

_Bryan Sisk:_ Through these interviews I'm performing, I find it interesting how much around the world pediatric palliative care relies on philanthropy and non-profit.

_Danai Papadatou:_ Yeah, that's true.

_Bryan Sisk:_ The States have reimbursement which has its pros and cons, but there is reimbursement through a lot of insurance companies. In the UK, in Greece, in South Africa, in Canada, a large portion of the budget for providing this care has to come from philanthropy. What do you think the reason is for that?

_Danai Papadatou:_ Well, philanthropists, some funders, let's say, have a personal experience with end-of-life care. At least in pediatric palliative care, they may have experienced the loss of a child. This becomes a driving force. Donations transform their pain into something positive that benefits several seriously ill children. The problem with some funders is that they want to associate their name with a building or something that is very visible, and palliative home care is largely “invisible”. Sometimes our running costs for services are extremely limited. We struggle to survive; I have to say, that after the economic crisis in Greece, things have become very difficult.

There are some foundations like the Maruzza Foundation in Italy. It's a private foundation that I think did a lot of good for Italy, and also moved the pediatric palliative care field forward in addition to helping develop pediatric palliative care in Italy. This foundation is the one that over the past ten years, organizes every two years, an international conference on pediatric palliative
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care. It depends of the, again, the funders. Especially in low-resource countries, such services are limited or inexistent. Pediatric palliative care is a luxury or it is viewed as a luxury.

_Bryan Sisk:_ One thing I'm curious about, do you think that these non-profits and philanthropic organizations have filled a need that would have continued to go unfulfilled? Do you think in any way that the philanthropic support of palliative and hospice care for kids has allowed governments to—the healthcare infrastructure in countries to be a little more complacent, because other people are taking care of it?

_Danai Papadatou:_ Yes, that happens. I believe that—[audio cuts out 00:39:28]

[Turns recorder off and back on]

_Bryan Sisk:_ We're back.

_Danai Papadatou:_ Ok

_Bryan Sisk:_ One thing I'm really interested in is understanding the role of philanthropy in the later role that the government played or didn't play. Did having philanthropic organizations take on this role of helping to promote palliative care in pediatric palliative care and hospice care—did that, to some extent, allow the governments to become complacent because other people were taking care of it, and it didn't become a priority for them?

_Danai Papadatou:_ Yes, I think in some countries, this is the case. In other countries, like the UK, the government at least participates partly. In other countries like Greece, for example, they don't even recognize the need. They don't even have in their agenda palliative care. It depends on the country. As long as there is philanthropy or, let's say, non-profit organizations that raise funds, the governments—most governments will not make it as their priority.

_Bryan Sisk:_ I'm interested in going back, also, to one thing you said a few minutes ago. You talked about how the approach in your pediatric oncology department was very holistic.

_Danai Papadatou:_ Yeah.

_Bryan Sisk:_ The main issue was when the kids were wanting to go home—

_Danai Papadatou:_ Yes, home.
Bryan Sisk: - for the end of their life. Could you describe what you mean by the holistic approach? What were they doing—

Danai Papadatou: Yeah. I'll give you an example. Families were introduced, for example, to the psychologist and social worker from the very moment of diagnosis and used our services without feeling that they were stigmatized. I heard the diagnosis at the same time that parents were hearing the diagnosis of their child. I was in the room with the oncologist.

When they went out the door, I was there for them and their child w all through the hospitalization. We never worked on a referral basis, but provided psycho-social services that were integrated into the team's approach. Personally, I rarely worked behind closed doors of an office. My services were offered in hospital rooms, the outpatient clinic, at the hospital's playground, even at the hospital's morgue.

Yeah, that approach was adopted by the entire team. By the physicians, the nurses, everybody. We were a team. We attended all the meetings, discussed all the issues that were raised. We, the psychologists, helped the physicians and nurses to cope with some families. They helped us to understand the physical conditions and the needs of some children and parents or the dilemmas they had. We facilitated decision making and listened to the challenges they were coping with. We created an approach that was unusual in most of the Greek hospitals.

Bryan Sisk: Yeah. Even outside of Greece, was this holistic approach that you're describing, from your awareness, was that common in other countries around the world at the time? Were you doing something that was pretty extraordinary there in Greece or in Athens?

Danai Papadatou: No, I think my experience in Arizona was similar. Fran Farrell was both a nurse and a social worker. She was very present from the moment of diagnosis. The next-door hospital in Athens, because we have two pediatric hospitals next to each other, functioned totally differently. Whenever a child was crying or a parent was upset, physicians and nurses called in the psychologist who provided services and left.

This was stigmatizing for families who felt that something was wrong. We didn't do that. We did something different. Many times, I worked with children through play and creative activities, and decoded some of the concerns to parents and to professionals so
they could better understand some of the issues that these children were struggling with. That's team approach.

_Bryan Sisk:_ From what you're describing, it sounds like a lot of on the ground clinical work. How did you balance that with the ideal of also doing research, writing up your experiences, and generalizing it so other people can learn from that?

_Danai Papadatou:_ [Chuckles] How did I balance that?

_Bryan Sisk:_ Yeah.

_Danai Papadatou:_ I don't know. I balance many things in my life. [Laughter] It's never one thing. Well, I have to say, there was a time in my life when clinical work was the priority, okay? When I went into the academia, I'm already 30 years at the university, I used this clinical work, and still use examples from my clinical work in my teaching. It's nothing strictly theoretical. It's theory plus practice. Research, yes. Research is not conducted for the sake of research or publication. It is research on issues that we need answers to. We don't know enough. That will help improve our clinical work.

The issues that were of concern to me and to my colleagues were issues that were very hot in our daily practice and in our daily work. The most recent research project we conduct currently at Merimna, through the pediatric palliative home care is focused on how families decide at the very end of life whether to care for their child at home or in the hospital.

We need to understand better the factors that affect these decisions. Yeah, we came up with some very interesting data that are helping us to help parents in their decision making, but also, illuminate the decision making process.

_Bryan Sisk:_ Another thing in this history that I'm really interested in exploring is the tenuousness of this development. How much do you think it would've changed the trajectory of what you developed there if you happened to have had a different oncologist who was less open, or be in a different hospital? How much of this do you think was inevitable and was going to happen versus how much of it relied on chance of the right people being at the right place?

_Danai Papadatou:_ I think it was—well, there are two things, okay? One thing is related to the right people at the right moment. I was lucky to have
an oncologist director in the team that was very open. She had the background—she had studied in the United States. She had the culture that was open-minded on these issues. At the same time, the second is associated with advocacy. Turning things upside down sometimes.

I remember I was not yet hired in oncology. I was still a student back then, volunteering my services in the pediatric hospital, when I experienced my first encounter with death. It was of a child who had renal failure. He was on dialysis and his death was sudden. Because it was so sudden, and I was very close to him, I wanted to see him. They didn't give me the keys to go to the morgue. I insisted. I got the keys. What I saw was terrifying, because the morgue was like a dump. It was located close to a place next to a small cabin with small animals the hospital used, how you say, for research purposes.

It smelled awful. It was terrible. I wrote immediately a letter to the director of the children’s hospital, reporting that, “This is unacceptable.” Until then, they never allowed parents to go there. So they painted the morgue. They put some flowers. Six months later, it was, again, a dump. It reflected to me that the culture of that hospital was not accepting death. Focus was on living and curing. Death was something dirty, filthy. Something to be hidden, set aside.

I made a huge fuss on the occasion of another child’s death. Again, this time, it was more effective. Of course, it's the people in the right place, but it's also some of these people—some of these professionals to have the guts, I would say, and the determination to push some barriers. Ida Martinson had to break down many barriers. Many other people in these fields. Sister Frances Dominica. Ann Goldman, who introduced pediatric palliative care in the pediatric hospital. Yeah, they had to go against the stream—the mainstream of pediatrics or medicine.

**Bryan Sisk:** If—

**Danai Papadatou:** It's both. Conditions and people.

**Bryan Sisk:** Following up on that, what do you think was the real spark that drove the development of pediatric palliative care as a specialty?

**Danai Papadatou:** It wasn't one thing. I think it was clinicians, researchers, and educators at the same time advocating for pediatric palliative care in different parts of the world. Ida Martinson and Betty Davies
were setting the first home care. Sister Frances developed the respite center, Helen House. Chuck and Donna Corr published and introduced in the university a course on children and death. That was a big thing back then.

Barbara Sourkes was probably one of the first psychologists who had something very comprehensive to offer, and publish to help define the role of the psychologist in this field. Bluebond-Langner conducted the research on dying children in an oncology department. All these people made a contribution in different domains; it was not only clinicians, or researchers and educators; all together had an effect.

I must say that the other thing that facilitated the process, was the National Hospice and Palliative Care organization—I don't know if you know that, in 1998, they invited us—I think we were 30 people who were contributing to the development of pediatric palliative care in our own country. They invited all of us to Dallas, Texas for a meeting to exchange knowledge, experience, and set priorities which would help to move pediatric palliative care forward.

Through that meeting, the ChIPPS project was developed.

_Bryan Sisk:_ Mm-hmm.

_Danai Papadatou:_ - if you are aware of that. It's the Children's International Project on Palliative Care/Hospice Services. This gathering was an excellent opportunity for the exchange of experiences, ideas, research, and education. There were different documents, compendiums, and research projects that came out of that collaboration. I personally had the privilege to collaborate with Chuck Corr and Gerri Frager on developing the training curriculum in pediatric palliative care, which was later published by NHPCO. There were many other compendiums that were published which moved the field forward.

_Bryan Sisk:_ How much did the adult hospice and adult palliative care movement affect the development of pediatric palliative care, from your perspective?

_Danai Papadatou:_ Well, the adult palliative care opened the way to address the taboo issues about serious illness, end of life care, and death. The adult palliative care offered an alternative approach to the care of the dying that was not driven by cure but by a personalized and dignified approach of caring for people at the end of their lives. Cicely Saunders and Kübler-Ross raised the awareness about the
patient's suffering, their needs and hopes, and advocated for their rights for a dignified life until the very end.

It kept also for decades, pediatric palliative care, under its wing. That was my feeling. It took some years before pediatric palliative care developed its own voice, independent approach, and activities. It held its own international meetings. It created its own organization and society. Still, it lacks a professional journal, for the publication of research in pediatric palliative care. We still publish in the journals that are more adult oriented.

Yeah, it had a big influence. I think, in some countries, adult palliative care still keeps under its wing, and perhaps its control, pediatric palliative care. Not everywhere.

**Bryan Sisk:** How do you think the relationship should be between adult and pediatric palliative care?

**Danai Papadatou:** Open communication and collaboration. The general principles are, in essence very much the same for adults and children. I think pediatric palliative should develop its own specialty. There are distinct differences between adult and pediatric palliative care. They overlap, especially when it comes to young adults who transition from pediatric to adult palliative care. There is a need for collaboration, in order to further develop the field but also space to develop pediatric palliative care more independently, too. Yeah.

I don't think that it must be a medical specialty. It is an interdisciplinary specialty that should include pediatrician, nurses, psychologists, social workers, and everybody else. My conviction is that they have to be trained together and learn from each other. Learn how to collaborate and put into practice their knowledge and skill as a team. We sometimes lack expertise in teamwork and working in collaboration to solving challenges and conflicts. Understanding better team dynamics and how they affect the care of children and the care of families. This is hardly ever addressed in most educational programs.

**Bryan Sisk:** Have you noticed a change over the years—

**Danai Papadatou:** Yeah.

**Bryan Sisk:** - from inter- and multi-disciplinarity to being more physician driven?
Danai Papadatou: It is physician driven. Still, greatly physician driven. Perhaps it's even more in adults than in children. Look at the training programs that are offered. Sometimes I'm skeptical. They are still very medically oriented, with limited topics on the psychosocial aspects, team dynamics, and self-awareness. Yeah. I don't know what to say about that.

Bryan Sisk: [Laughs] That's plenty. Looking more longitudinally over the last 30-plus years of your career, what have you—what have been the biggest changes in the care provided to these children who are suffering and dying from serious illnesses?

Danai Papadatou: First of all, there is a greater interest. We had the EAPC meeting in Berlin a month ago, the European Association for Palliative Care. For the first time ever, there was a full day from 8:00 in the morning till 6:00 in the afternoon, dedicated to pediatric palliative care.

Bryan Sisk: Wow.

Danai Papadatou: That was a big thing. The organizers anticipated that there would be 150 people. Two hundred maximum. Nine hundred signed up for this one-day meeting. I think this is an indication of a growing interest in the field. Yeah. It's a field that is in process of development. That's how I see our field. It has some strong assets. I think it flourishes whenever there are transformational leaders who inspire others, wherever there are effective teams that provide high-quality care, wherever there are resources, and, of course, legislation that promotes pediatric palliative care.

There are areas that we need to still work more. One of these areas, is a stronger advocacy for accessibility to pediatric palliative care for every seriously ill child and family in the world. Very few children have access to pediatric palliative care, and I'm not talking right now only about the UK or western countries. I'm talking about the globe. That's one area where we need to do something more efficiently.

We need better training and education of professionals who seek different levels of expertise. I don't know if you're aware, the EAPC has proposed three distinct levels of education in children's palliative care, which depends a lot on the professional's level of involvement in the delivery of palliative care services.

Now, from what I realize here in Europe, there are several obstacles that prevent accessibility, affordability, sustainability of
such courses. Many of these courses are rarely evaluated with regard to their outcomes. We need stronger training programs. We have guidelines how to develop them. I'm rather skeptical about—and very reserved about training programs which are very short term, have a biomedical focus and address exclusively issues related to symptom management and pain control.

We need to teach—introduce students from their undergraduate studies in the concept of palliative care and pediatric palliative care. There is much more that we need to do, with regard to the provision of palliative care in situations of a humanitarian crisis: I live in a country that has been exposed to thousands of refugees who come across, and want to settle somewhere in Europe—not in Greece, necessarily. We have done nothing about children or even adults who are in need of palliative care.

I don't know that there’s much that is being done internationally for people who are affected by such humanitarian crisis or mass disasters, which are very common nowadays. We need to identify the obstacles that prevent us from providing these services and undertake collectively action in order to bring about change. I don't know what you asked me initially. [Laughs]

_Bryan Sisk:_ It was a great answer.

_Danai Papadatou:_ I think I'm going all over the place. [Laughs]

_Bryan Sisk:_ No, that was perfect. You've told me really what some of the strengths are. What some of the areas of the field that need to really grow still. Thinking about all of these changes, I'm going to ask you maybe a hard question, but what is your favorite contribution that you have given to this field?

_Danai Papadatou:_ My passion about the field. My belief in the value of pediatric palliative care and my ability to communicate this and inspire others.

_Bryan Sisk:_ Perfect. Well, I've really just got one question left. This is asking you to dream for me. If budget, and politics, and all of the things we talked about, the training issues, if none of those were an obstacle, what would you ideally want care for these children to look like in another 10 years?

_Danai Papadatou:_ To integrate pediatric palliative care in general mainstream pediatrics in addition to developing specialized services. More solid research that would enhance good practices in pediatric
palliative care in different cultural contexts. I would say one more thing, which is important to me: greater collaboration between pediatric palliative organizations. I like the idea of twinships among organizations, services, and teams across the world.

I strongly believe that we have to learn plenty from each other. We can learn much more. We would benefit more from rich collaborations. Funding, for example, should strengthen these collaborations among countries. That would mutually benefit new programs, new initiatives, new ideas, and experiences. We need leaders to inspire these kind of priorities and these kind of twinship initiatives.

I strongly believe children are citizens of the world. The responsibility to care for them when they suffer from a life-threatening illness has no borders. Instead of looking what's happening in our own yard, let's think more globally and collaborate. For the moment, this is not happening. I wish in 10 years we will be at a better spot, at a better position to create more rich collaborations, because there is knowledge, there is expertise, there is experience. We need more than getting together in conferences and presenting some of our work. We need stronger collaborations and ongoing collaborations.

_Bryan Sisk:_ Wonderful. Well, this has been phenomenal. I'm really grateful for your time. Is there any other part of this history that you think I haven't touched on that you wanted to tell me about?

_Danai Papadatou:_ [Laughs] Well, there is so much to say about pediatric palliative care, but I think the questions that led the discussion were very helpful to me and covered a great deal. I thank you for giving me the opportunity to share some of my experiences.

_Bryan Sisk:_ Great.

_Danai Papadatou:_ It has been truly a positive experience for me, too. Again, I want to congratulate you for this initiative to gather the stories of people who have been in the field for years and have made a difference.

_Bryan Sisk:_ Great. Well, thank you.

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