Jonathan Singer: Today’s podcast is about social work with children who have cancer, also referred to as pediatric oncology social work. Although pediatric cancer is relatively rare event, making up less than 1% of the cases diagnosed annually, that single case affects the lives of countless others. From a treatment perspective, when a child is diagnosed with cancer, the whole family is diagnosed with cancer. Children are most likely to get cancer in their first year of life, and least likely between the ages of 5 and 14. If you are white kid in the United States you are nearly two times more likely to get cancer than if you are black. One in 300 boys and one in 330 girls will develop cancer before the age of 20. Every year 2500 children die from cancers with names like Acute Lymphoblastic Lukemia (ALL - cancer of the bone marrow - the most common childhood cancer), Hepatoblastoma (cancer of the liver), neuroblastoma (cancer of the central nervous system), Ewings sarcoma (bone cancer), Hodgins Lymphoma (cancer of the lymph nodes), and Wilms tumor (cancer of the kidney). Notice that the most common forms of adult cancer such as lung, breast and colon are not included on this list. And it is not just that children get some cancers and adults get others. Among children, the cancers most often found in infants and toddlers are not the same as the cancers most often found in teenagers. For children today, getting a diagnosis of cancer is not the death sentence it once was. Before 1970 most children who got cancer died. Today, survival rates are nearly 80%. Currently there are about 270,000 survivors of childhood cancer. Consequently pediatric oncology social workers need to know as much about working with survivors of cancer as they do about issues of death and dying.

To help me get a better idea of what being a pediatric oncology entails, I spoke with Dr. Barbara Jones, social worker and faculty member at the school of social work at the University of Texas at Austin. Dr. Jones is the immediate past president of the Association of Pediatric Oncology Social Workers, on the editorial board for the Journal of Social Work in End-of-Life and Palliative Care, and the co-director of the Institute for Grief, Loss and Family Survival at UT-Austin. Dr. Jones recently designed and taught the first social work course in the United States on psychosocial oncology. In today's podcast, Barbara and I talked about the role of a pediatric oncology social worker in a multidisciplinary team, with the child, with the family, in a hospital setting and in the community. We talked about best practices for working with kids with cancer and the role of research in pediatric oncology social work. She talked about practical and ethical issues in pediatric oncology social work such as consent and assent, how to accurately assess a child’s pain, and how social workers can take care of themselves. Barbara told some powerful and moving stories about the work she’s done with children who have died and children who have survived cancer. We ended our conversation with a discussion about how social workers get training in pediatric oncology social work, and what some resources are for social workers who would like to know more about working with children with cancer.

One quick word about today’s podcast: I recorded today’s podcast using a *Zoom H2* recorder on location at the *Society for Social Work Research (SSWR)* annual conference. If you listen closely you can hear the sounds of San Francisco in the background: a clock chiming, busses loading and unloading passengers, and even some pigeons congregating outside of the interview room. They don’t detract from the interview, but I wanted to give fair warning in case you were listening to this podcast anywhere were those sounds might be cause for alarm.

So, without further ado, on to the interview with Dr. Barbara Jones and Pediatric Oncology Social work.

**Interview**

**Jonathan Singer:** Well, Barbara, thanks so much for talking with us on the podcast today about kids and cancer. And my first question for you is, what is pediatric oncology?

**Barbara Jones:** Well, Jonathan, I’m really glad to be with you today and talk about this area that I’m very passionate about. When you asked me, do you mean pediatric oncology or pediatric oncology social work?

**Jonathan Singer:** Is there a difference?

**Barbara Jones:** There is a difference. Pediatric oncology is a multi-disciplinary field of care that encompasses everything from physicians to nurses to child life specialists to social workers, nutrition, chaplains, and that’s the full interdisciplinary care. Pediatric oncology social work is a specialty discipline, both within social work and within pediatric oncology that focuses on social workers caring for, and working with, children and their families with cancer.

**Jonathan Singer:** So, what is the role of a pediatric oncology social worker?

**Barbara Jones:** That’s a very big question. So, pediatric oncology social workers can have many different roles in both community settings as well as in hospital settings. So, they can be working with a child and their family from the moment of diagnosis to help with managing, kind of helping to hold, that emotional news, which is really difficult. So, right from the very get go, ideally you would have that pediatric oncology social worker there upon diagnosis. That person would stay with the family throughout treatment and posttreatment, whether that resulted in a palliative care end of life situation or survivorship. Across that whole treatment continuum and posttreatment, pediatric oncology social workers provide emotional support, they provide assessment, clinical assessment, they provide mental health and emotional interventions, for both the children, their siblings, their parents, sometimes their community, sometimes their school setting. I found in my practice that sometimes pediatric oncology social workers also play a role in the multidisciplinary team to help some of the other disciplines deal with the emotional impact of working with children with cancer and their families. Obviously, pediatric oncology social workers also participate in advocacy, they help identify resources for families and children, they spend the time, sometimes we serve almost as a witness to the experience, spend the time with the child and family to help them adjust to the experience they’re having,

whether it be a hospital stay, an invasive treatment, just kind of learning the identity piece of, now I’m a kid with cancer, and what does that mean, how do I relate to my classmates? I could go on here, Jonathan, so I’ll stop there.

Jonathan Singer: As you’re describing it, it sounds like a pediatric oncology social worker does exactly what we talk about in schools of social work as sort of eco systemic practice, you know, working with all the different levels, the micro, the meso, the macro, the communities, the families, the kids, working with many different service providers. So if there was a social worker listening to this podcast who recently started working in a situation where he or she was going to be working with kids with cancer, what sort of things would they need to, would be helpful to know about or think about in terms of being able to provide the best service as possible?

Barbara Jones: That’s a great question. Social workers working with kids with cancer and their families need to understand that what the children and the families seem to need the most is that one thing, they need someone to talk with about their feelings, about their fears, about the experience. They need someone to communicate and help them figure out what’s going on for them. And so sometimes that is talking, sometimes those are different interventions like play interventions, but basically they need support around this very difficult process, and how am I going to get through this and manage and, kind of, feel well, as well as I can feel throughout the process. They also need advocates that help them with things like making sure that they understand what’s happening. Sometimes in a medical setting, entering a hospital’s like entering a different land if you don’t speak hospital, and so they need a translator. They need somebody to say, you know, many times in my practice I’d be sitting with a child and family, the doctor would come in, even some of the best communicative doctors would explain what was happening and then leave the room and then the child or the family or both would turn to me and say, “What did she just say?” Now, some of that is because medical is hard to speak, some of that there were actual also language barriers, sometimes that’s also just about the emotional trauma of hearing that your child has cancer, you don’t take it all in at once. Once you hear that, you don’t hear a lot of the other words and so you need someone there to help you say, this is what happened, and also to, sometimes, we’d sit right with them and write down, what questions do you have when the doctor comes back? What part is still confusing to you? And I’d pull the doctor or the nurse back in and say, “Let’s go over this part again because this is confusing.” So, a translator, they need an advocate to help them get services. Sometimes it’s the traditional financial support services that we think about, applying for financial support. There are many pediatric oncology social workers that actually that whole aspect of support happens in another part of the hospital ‘cause it’s pretty technical, and that frees up the social workers to provide the emotional support, but even having access to the people that are going to help you fill out those forms. But, getting support, getting resources also means things like having the opportunity for Make-A-Wish, having the opportunity to have your family with you. One of the most dramatic occurrences that I can think of that I think many of my pediatric oncology social workers colleagues have similar stories, is a young boy who was facing the end of his life and he was well maintained in the hospital, what I mean by that is his pain was under control, his family was supporting him, but he really really wanted to see his uncle who lived in Puerto Rico one last time. And the kid was able to articulate that and the family did not have

the resources to get the uncle here from Puerto Rico. So, what are we gonna do? So we work with all these amazing organizations that provide, there are many organizations that actually will provide free flights for kids to get treatment, not as many for families, but we spent one very long day on the phone with everyone I could think of until I was able to get an organization to agree to fly that uncle for free from Puerto Rico to upstate New York so this boy could see his uncle. And sure enough, after we got the uncle there, the boy died, and he needed to have his uncle there. So sometimes getting resources is beyond what we might think about in another setting.

Jonathan Singer: So, coordinating resources, obviously a huge part of it, also being a translator. And it sounds like a lot of what you’ve talked about is work in a hospital but you mentioned in the beginning that you don’t have to work in a hospital to be a pediatric oncology social worker. What are some of the other settings that pediatric oncology social workers work in?

Barbara Jones: There are a lot of not-for-profits in the community that might provide support and services to kids with cancer, Make-A-Wish is one I think about, Cancer Care is another one, so lots of places, Super Sibs which is a wonderful organization that provides resources to the siblings of children with cancer who are often overlooked and forgotten just because the family needs to, those of us that all understand eco systems understand that the family rallies to support the critically ill child and there’s plenty of research that tells us that siblings sometimes have long-term effects from that. So, Super Sibs is one that comes to mind. So there’s lots of different organizations, and in fact, I have the fortune of meeting a lot of them at the Association of Pediatric Oncology Social Workers which is a very specialized social work membership organization for pediatric oncology social workers that meets annually and where we have people who are practicing in clinics, and hospitals, and in the community come together and talk about how do we best, what our best practice is to support these kids as they go through this process.

Jonathan Singer: So since you just mentioned best practices, what are some of the best practices, and are there evidence based approaches for working with kids with cancer and their families?

Barbara Jones: That’s another great question, and that’s, I hope, where my career is taking me right now. I practiced clinically as a pediatric oncology social worker and really got into social work research to begin to answer that question. How do we best serve children with cancer and their families, and what is the evidence? And, I’ll tell you, like a lot of our fields, we don’t have rigorous randomized control trials that tell us, do this, not that. Also, we have to factor in that each child is unique, each family is unique, each moment is unique. So sometimes when I’m asking a child or a family, how are you doing, I don’t even ask that question anymore. I’ll ask them, how are you doing today, or how are you doing since lunchtime, or how are you doing since the doctor came in? So my intervention is going to be changed based on how they’re doing and how they’re doing changes all day long. So that’s one thing that I’ll say. But I did have an opportunity to do some research myself that asked social workers about what they thought were the best practices, particularly in the end of life. That was helpful and illuminated some of

the things and that’s where I get some of these ideas about talking about feelings, pain and symptom management is actually a role for social work that we sometimes don’t think about, supporting the child and the family in the community and those types of things. We do have some good Institute of Medicine reports that have come out recently that are very helpful for pediatric oncology social workers. One is called “Cancer care for the whole patient” that focuses a bit more on adult but still has some great recommendations, pretty recent publication, I think 2008. There’s also an Institute of Medicine report called “When children die” that looks at the palliative care needs. So we have that kind of evidence, we have the kind of collective community evidence bringing experts together for years to talk about what is best. There’s also Institute of Medicine reports on childhood cancer survivors, so we’ve got that to build on. But every single one of those reports says what is needed is more research so I spend a lot of my time trying to have clinical social workers think about where do they fit into research and making sure that researchers are staying grounded in practice, as a lot of us do, but trying to do that translation between the practice of pediatric oncology social work and the research of pediatric oncology social work.

**Jonathan Singer:** So what are some of the things that pediatric oncology social workers who are in the field right now do to contribute to this knowledge base or this research? And I’m thinking specifically of social workers who might not necessarily be involved in an actual study. What’s the bridge, what’s the connection?

**Barbara Jones:** That’s a good question. So, there’s this whole continuum obviously there of those of us who are now playing the academic role, although I still really see myself as a clinical pediatric oncology social worker and I hope I never quite lose that identity. But then across the continuum there are folks that are in the hospital that might be part of a multidisciplinary research team so they might serve in that way. The other thing that social workers do a lot of is helping patients and families understand informed consent. So, most children that are treated for cancer are on clinical trials. This is a bit different than adult cancer. In fact, part of the reason I mentioned to you earlier that we see the survivor rates jumping so much in the past forty years, the survival rates for childhood cancer have jumped to the point that a child diagnosed today has something like an 85% chance of survival. That’s because close to 100% of these kids are on clinical trials, so we are improving the science of treating kids with cancer all the time. And social workers are in there, they’re explaining informed consents, sometimes they’re getting informed consents, sometimes they’re helping if there are ethical issues around informed consent. So most of pediatric oncology happens in a context of research and social workers are right in the middle of that like everything else. And then there are also social workers that are also PIs on their own intervention studies too.

**Jonathan Singer:** So, you just mentioned that nearly all kids with cancer are involved in some sort of clinical trial and that that’s one of the things that has contributed to this incredible increase in survival rates and that’s different than adults. And so, one of the things I was wondering was, how is cancer in children different than cancer in adults?

**Barbara Jones:** Do you mean medically or psychosocially or…?

Jonathan Singer: I think probably in general, but more specifically for the role of the social worker.

Barbara Jones: Ok, thank you. Well certainly when a child is diagnosed with cancer, the entire family is diagnosed with cancer. Now, we can see that’s true for adults too, right, and any of us who have had cancer in our family know that when somebody is diagnosed, everybody is involved. But, certainly in pediatrics, it’s much different because the child is not even legally old enough to consent to their own treatment. So, we have some major issues here about consent and assent, and so parents are legal medical decision makers because of that. We have plenty of occasions where parents and children don’t agree on what should happen, whether it’s starting treatment, stopping treatment. So that’s another big role for the social worker is facilitating communication within the family, and then between the child and the family, and then between the child and the medical team, and the family and the medical team, there’s a lot of communication facilitation that goes on.

Jonathan Singer: I’m just gonna interrupt real quick. So, when you say consent, you’re talking about the person who’s legally available to say “yes, we want this,” and when you talk about assent, you’re talking about what kids give because they actually don’t make their own decisions in that sense.

Barbara Jones: Exactly, thank you for clarifying. So yeah, “consent” is the legal term and “assent” is something that we should be getting in most cases. And most children’s hospitals work very hard to get consent and assent for treatment so that not only does the parent legally say, “Yes, my child can enroll in this study and my child can get this treatment,” but the child has some buy-in too and understands in their developmentally appropriate way what’s happening to me, and understands what it means to receive medical treatment. So, issues of family dynamics are huge because this idea about when a child is diagnosed the entire family is diagnosed. And what we know about families is that if you change something in that system, everything moves, and so the equilibrium is thrown off. And social workers are engaging right away with both the child and the family. How are they gonna get through this? What are they gonna do? What’s their plan? Many times, if it’s a family where two parents were working, one has to stop working to help the child through the treatment. How are they going to negotiate that? What does the mean for them financially, emotionally, even in the parents own identity, which is not something they’re thinking about at that time, but in the long-term that can become impactful. If there are economic struggles already, which many times there are, how do we support a family that might have already been at their absolute capacity for dealing with struggle, and bring out the most resilience we can in them? And many times I’ve been surprised at how incredible families are in their ability to cope with this difficult diagnosis. So, issues of consent and assent, issues of family dynamics. Issues of developmental stage that a child who’s four is very different than a child who’s fourteen. So, in pediatrics, we’re treating from children who are non-communicative to the adolescent who might be extremely communicative and we have to figure out how to communicate across the spectrum, how to make sure information is age appropriate. A story that I have told before in my classes and I will tell you now is that kids

are very very literal and so for many types of cancer treatment, one of the standard methods of moving forward is to have the child have a porta-catheter inserted actually under that skin in the chest. It’s a way to draw bloods, administer chemotherapy, and not have to stick the kid a million times, right? So it sounds kind of barbaric that we would insert something in the child’s skin but it actually ends up being less intrusive, less painful. It’s a surgical procedure, we get consent and assent from the child and the family for this but I have, it’s a difficult thing to comprehend, we even have both our colleagues in social work and child life even have kind of these dummies that have examples of what it looks like. So you can explain this to a child, but you have to check in with kids and find out, do they understand what we’re saying? So, one time I was working with a team and the team was a very strong, communicative team, doing a fine job, or so we all thought, of communicating and talking about a porta-cath and inserting a porta-cath, and da da da da, and explaining it, and the child was there and the grown-ups all left the room and the kid looked at me and said, “Are they gonna put a cat in my chest?” because all he heard was “cat.” So, while that’s an extreme example, that’s how literal children are. That’s how we really have to check in. So language issues, developmental issues are important, and then sometimes ethical issues. Ethical issues come up over this idea about who decides the treatment and what do we do if there’s disagreement? And also ethical issues come up about, in pediatrics, those of us in the medical team, we care a lot about these kids. That can impact, you know, physicians and how they proceed. They’re still going to be following their protocols, but certainly their emotions come into play too. So there’s lots of ethical issues that can come up. One other area that I just want to talk about here too is, I’m not sure that we’re always really good at assessing children’s pain. So I am concerned that we do a good job and that social workers should have a role in finding out, what does pain mean, how is pain experienced, how does this child express pain, how will we know they’re having pain, how do we make sure that we reduce that as much as we can?

Jonathan Singer: You talked about a number of different areas in which pediatric oncology social workers practice in the hospital, outside the hospital, and a number of different things that they do. Is there specialty training that a social worker has to get or should get or usually doesn’t get in order to be a pediatric oncology social worker?

Barbara Jones: Most people do not get this training in their schools of social work unless they happen to be working with a professor who has a passion about it so there’s a few people who get it at the University of Texas at Austin because I cannot help but weave it into the classes. And, in fact, we have an oncology course in our social work program. But for most practicing pediatric oncology social workers, they get it on the job and that’s both a hard way to learn and sometimes a good way to learn. The best things that I’ve ever learned about pediatric oncology social work, I will tell you, I have learned when I have been smart enough to be quiet and to listen to the kids and families. So, there’s some learning that has to happen there. However, there’s plenty of ways that we can help pediatric oncology social workers before they get these jobs and after. A lot of people come to pediatric oncology social work after they’ve been doing something else. I did. I had a few other jobs before I came to this and found it as kind of my passion. So, there’s usually a good, strong skill set in social work, and then how do I translate that to this population? We in pediatric oncology social work talk about how there seems to be

a divide, that somewhere in the first couple of years, and I don’t know that this has been empirically tested, people figure out whether or not this fits. And so, you get in, you try it, you see if you like it, if it isn’t a fit, you move on pretty early. If you don’t move on, there’s some serious longevity in this field. There’s people who really see this as a calling. One of the best ways to get specialized training is through the Association of Pediatric Oncology Social Work where we have an annual conference and meeting and that is where we talk about direct practice. How am I gonna help people present both their empirically supported and their practice supported interventions, applications? The learning there is tremendous. In fact, we have a whole new workers seminar that we do for folks who are new in the field to help them through that. So that is one way that we get that kind of training out there. Sometimes you can get specific training online. So NASW has some trainings online about oncology social work. It’s not pediatric specific. Sometimes you can get specialized training in end of life care which can be helpful to you, and you can get specialized training in pediatric end of life care. We do have a social work in hospice in palliative care network that meets annually as well, we’re meeting this year, that talks about specifically how do we do palliative work. There’s also some tremendous training opportunities that come out of the Lance Armstrong Foundation, the American Cancer Society. So you have to seek it out, but there are ways to get some of that training. And then a lot of it is done by mentorship, really, by that clinical supervisor there in the hospital, by reading everything we can, by talking with people, and coming together with colleagues.

Jonathan Singer: So how might a social worker support a kid and family at the end of that kid’s life? And, conversely, how might a social worker support a kid and a family who’s surviving?

Barbara Jones: Well, as we talked about, each situation’s gonna be unique, but there are some ways that we can think about supporting children and families at the end of life. One of those is children and families often need a witness to the experience, so just being present and figuring out how to be there without being intrusive, figuring out how to offer interventions that may be nonverbal, that may, you know, sometimes it’s about struggling with your own futility because you feel like you want to do so much, you’re probably pretty heart connected to the family and you can’t take it away, you can’t fix it, you can’t even take the pain away, you don’t have a right to, so how am I gonna sit there? And so getting comfortable witnessing and sitting with pain, sounds kind of harsh, but really, being in the presence of that and not shrinking is incredibly supportive. I mean, you think about the times in your life when you’ve been really struggling with something, to have somebody who will just listen and says to you, “I can’t fix this, but I’m not going away, I’ll be here,” that’s the intervention. So, I think about that. In addition to that, we need to certainly do a full assessment and think about cultural contexts in all of that. But it’s important to do the best we can to facilitate communication from the child, with the child, make sure the child understands what’s going on. I will ask children, tell me what’s happening, and even if they say, well it’s right there in the report, yeah, I know but I want to hear what you tell me. Because I’m checking for the kid who thinks he’s having a cat put in his chest, you know, I’m checking it out. I’ve learned the hard way to ask. So at the end of life, certainly, I’m going to say, so tell me what’s going on, what do you think’s happening? It’s not uncommon at all for children to protect their parents from their own suffering, even dying children. And so I’ve had plenty of kids say to me, “Barbara, I know things aren’t going well and
I can tell ‘cause I can feel, I know my body, I’ve had cancer off and on for ten years and I know something’s different,” or, “I can just feel it in my doctor’s face, you know, I know my doctor well enough, I’ve known him for ten years, but don’t tell my mom, don’t tell my mom I’m dying because I don’t want her to be upset.” Conversely, the mom may also get you in the hallway and say, “I know what’s going on with him. Let’s not tell him, I don’t want him to lose hope.” So there’s a place for a social worker, right there, to help each member of the family be able to communicate directly with each other because kids have the same right to end of life planning, to end of life communication. If you think about the work that hospice does both with adults and with children, kids have a right to have those conversations with their family, to say, “I love you,” to say, “Don’t forget about me.” All those things, kids have a right to say that, parents have a right to it, and so we have to sometimes help bring up the uncomfortable conversations. And it’s about being honest. It is very hard to tell anybody bad news, very hard. It’s hard for doctors to tell adults bad news, it’s really hard to tell a kid that you’re likely to not survive from this disease. That’s very difficult. So we also help tell. We help saying, if we’re at that stage, we may say, “Can I, you know, do you want me to be with you when you talk with your child? Do you want to have the doctor do it? Should we do it? How are we going to do this?” So we’re constantly getting the message out about honesty. Sometimes there’s actual end of life planning. I had one child I worked with that part of her end of life plan was she had a bunch of stuffed animals and she decided who was getting what. That was her end of life planning. Somebody had to ask her, so she got to do that and that was incredibly meaningful. I have one of them myself, so, to this day in my office. Also, working with the family about arrangements. And we really can, I think it is a misnomer to say that that completely obliterates hope because I think you can have hope in the midst of this, it’s just that what you’re hoping for changes. So, in the beginning the family may hope for cure, the child may hope for cure, we may hope for cure but if you get to a different stage, you might hope for, I’ve had parents say to me, I hope my child is pain-free, I hope I have the courage to get them through this, I hope that we will, you know, bring in all their best friends and, you know, their favorite items, I hope that we can get them home, I hope they can die...so, my point being is that we have to keep facilitating hope while maintaining honesty. So it’s a lot about being a witness, being an advocate, being a communicator, being willing to start some difficult conversations, being willing to intervene when you don’t know what to do. That is a scary place but to just say, “I’m gonna sit here.” And sometimes I’ve actually said that to families instead of just sitting there, like they might wonder why am I still sitting here? No, I have said to families, I’ll, you know, if you like, I can just be here. So all of that is very very helpful, if we think about end of life decision making, making sure that families are fully informed about what their choices are. And again, advocating for pain control. Sometimes we don’t get that right. Social workers can take a role in that advocacy. Social workers can also use non-pharmacological interventions to assist in pain control. So that’s when I think about end of life, those are ways that social workers help. We think about survivorship, there are, in addition to the children that we might work with directly, so the pediatric oncology social worker works with a child who then survives. Ideally we have a way to help transition that child from being on active treatment to this identity as a survivor. Both transition them kind of emotionally, but also, if I was six when I got treated, I may not even know what happened to my body, right, but now I’m sixteen or I’m 26, I’m going for a job, I’m thinking about getting married, maybe having a kid, I need to know what happened to my body,
I need to know what the, what we call “late effects” are, common late effects, whether there are carbon toxicities or other concerns, infertility, fertility concerns. Ideally we’re having those conversations on the front end so we’re doing some preventative work particularly around fertility. But, making sure that the child, now survivor, sometimes adult, has actual written information about what happened, what their treatment was, and that they can take that with them through their lives so that when they meet a new doctor as a 26 year old, they can say, I had cancer, this is what happened, these are the treatments I got, and that helps them have long term healthcare, health promotion. There are some risk factors post cancer and they’re dependent upon the cancer but it is really important to stay in tune to health promotion needs for this population, risk of secondary cancers, risk of cardiac event, etcetera, it really depends of the cancer. But knowing what those are and then helping create health promoting interventions for these kids-slash-adults is really really important. Ideally this is done as an interdisciplinary team. The other thing that I’ll say is that recent estimates say there’s something like 270,000 childhood cancer survivors in the United States right now so you may not be working in the childhood cancer setting and you may be working with a childhood cancer survivor. So being able to figure out, is that part of a person’s narrative? The person I meet at 29 in a couples session, how do I find out if that’s part of their narrative ‘cause that might be impacting their life now, it likely is impacting their life now or their identity. So, keeping open to the fact that there may be people who have had this experience who might not disclose it upon first meeting. In fact we’ve done some research around how and when people disclose so that’s another issue. People don’t always come out and say, “Hi, I’m a childhood cancer survivor,” but it may be impactful for you as a clinician in another setting too.

**Jonathan Singer:** So, Barbara, thank you so much for talking with us today about pediatric oncology social work.

**Barbara Jones:** Well, thank you, Jonathan, for the opportunity because, as you can tell, I feel very passionate about these children and their families and about the role that social work can play to help them. So I was really glad to be here.

--- End ---

References and Further Readings


Websites
- Association of Pediatric Oncology Social Workers [http://www.aposw.org/]
- CureSearch: The Children's Oncology Group and the National Childhood Cancer Foundation [http://www.curesearch.org/]

Community-based not-for-profits that provide resources to children with cancer
- Cancercare [www.cancercare.org/]
- Supersibs [www.supersibs.org/]
- Make-a-wish [www.wish.org/]

Full-access articles and books

Institute of Medicine

Social Work

Other
- Childhood Cancer: Late Effects of Cancer Treatment [http://www.cancer.org/docroot/CRI/content/CRI_2_6x_Late_Effects_of_Childhood_Cancer.asp]

Recommended APA (6th edition) format for citing this podcast: