

Episode 113 - Dr. Barbara Jones: Adolescent Cancer Survivors: Identity Paradox and the Need to Belong

[00:00:08] Welcome to in social work. The podcast series of the University of Buffalo School of Social Work at www.insocialwork.org. We're glad you could join us today. The purpose of in social work is to engage practitioners and researchers and lifelong learning and to promote research to practice and practice to research. We're in social work. I'm your host Peter Sobota. Thanks for downloading more than 300000 of our podcasts. We'd love it if you took a minute to tell us what you like or don't like about them and what you'd like to see us do next. If you're an educator and you are using our podcasts in your courses please let us know how. I know some of you are as I've seen them on course syllabi out there. So let us know. We'd be thrilled to hear from you. Hello my name is Charles Sims and I am the host of this episode of in social work the National Cancer Institute estimates that over one point six million people were diagnosed with cancer in the United States in 2012. In recent years there have been great strides made in the diagnosis and treatment of all types of cancer as a result in general cancer death rates have fallen and long term survival rates continue to increase. This is especially true for children and for those after age 40. However for those in their mid teens to mid 30s the news has not been as positive. Dr. Barbara Jones is an associate professor and codirector of the Institute for grief loss and family survival in the School of Social Work at the University of Texas at Austin.

[00:02:04] There she also holds a courtesy appointment with the Center for Women and Gender Studies Dr. Jones's social work practice experience has included 15 years as a clinical social worker with homeless and runaway adolescents bereaved parents grieving children and children with life threatening illnesses. She has also been involved in community organizing and policy work around HIV and AIDS and health care needs of children. She has held administrative positions in programs that provide services to pediatric cancer patients. Dr. Jones is the president elect of the Association of pediatric oncology social workers and a steering committee member of the network of social workers in palliative and end of life care. Dr. Jones consults and lectures nationally and internationally on issues of pediatric palliative care grief and loss in the role of social work in health care. Her latest research endeavor is a study of the meaning of surviving cancer for Hispanic and Latino adolescents. And it is funded by a grant from the Center for Health Promotion Research at the University of Texas at Austin School of Nursing. In this episode Dr. Jones discusses the developmental and psychosocial effects of cancer on adolescents and young adults. Dr. Jones speaks to the need to understand the unique needs of the adolescent and young adult. She also explains how these unique needs can complicate the continuum of care as well as important developmental processes. Further Dr. Jones suggests strategies of intervention to consider when working with this population. Dr. Jones was interviewed by Anthony Guzman director of the school of social works online programs. I'm Anthony Guzman director of online programs at the university. Buffalo School of Social Work.

[00:04:12] Here with me to talk about psychosocial and health promotion needs of adolescent and young adult cancer survivors is Dr. Barbara Jones. Dr. Jones thanks for joining us today. I'm glad to be with you. Could you tell us a little bit about your current research. Sure. My research is really dedicated to understanding the needs of both children and adolescents and young adults with cancer and their families so I look at how do individuals this young who have gone through a cancer experience make meaning out of that experience form an identity integrate that experience into who they are today and then what can we do as social workers to best help them and their families survive and thrive. So what prompted you Dr. Jones to get involved in this line of work or what sparked your interest. Well I'm a bit of an accidental researcher as some of us are. I was a clinical social worker for many years and my real passion was working in pediatric oncology. So in that role

I worked with children who were diagnosed with cancer and their families. And one of the things that I noticed was that for the adolescents it was a very unique developmental stage to have to go through cancer treatment because they were at that time as we expect when they would be branching out and pulling away from their family and forming who they are and then to have a life threatening diagnosis during that time really interrupts what's happening for them and caused a unique set of concerns that I became increasingly interested in helping and understand better.

[00:05:45] I think that lays perfectly to find out what is important for us or to study adolescents and young adults who are battling with cancer. Well as I was just saying there a unique group in terms of their developmental stage but it's also true that in the NCI would report this that for adolescent and young adult cancer survivors NCI defines that group as 15 to 39 year olds. But even if we focus at the younger group there that well cure rates have gone up for pediatric cancers and cure rates have gone up for other adult cancers. There is a real gap right in the middle. So we are really needing to focus on how do we improve cure and care for adolescents and young adults with cancer. And then you add to that that there are some very unique challenges that this group faces. Part of the reason that the cure rates are lower is that this group of young people who think about a 17 year old that person may be treated at a pediatric center or they may be treated at an Adult Center. So the protocol that they're treated on is not necessarily consistent where pediatric cancer is part of the reason that we have seen an increase in cure rates. And we've seen dramatic cure rate increases in the past few decades. Some cancers are 80 90 percent curable. Upon diagnosis is because we have controlled studies that tell us how we really target cancer therapies. And so for the adolescent young adult group it's such a wide range and they're not all treated in the same consistent settings. So they often have different rates of cure. Also we have a low suspicion of cancer in this young group so if a 22 year old is having a pain in their leg.

[00:07:25] The doctor may really understandably say well you need to stretch more after you finish your athletic activities when in fact it could be the signs and symptoms of an osteosarcoma. But we may not expect that because cancer suspicion is super low in young people because it's really rare. So then what. Or how are their identity and social relationships for this group of young adults and adolescents affected. There really are some unique psychosocial challenges that this young group faces not the least of which is school and work difficulties so if you think about how important the peer group is in the Adolescent and Young Adult Developmental timeframe to be pulled out of that peer group is very difficult. And so they often report feeling isolated feeling like they missed out on some major developmental milestones feeling a little cheated about that feeling like they lost friends and then so when they get to a place that they have survived then they say Well really the past three years I've been hanging out with the nurses at the hospital so I really got more friends and I'm better at relating to people much older than me. But I also missed out some important steps. So when I get back into my peer group I don't quite know how to enter. And I've had this very unique experience that here's the paradox sometimes makes young people seem very wise beyond their years because they've had to cope with something that is atypical developmentally atypical off time you would say. And yet they're also young because they've been isolated from their peer group. So this paradox presents itself. So peer difficulties can exist for some time.

[00:09:07] The research shows us that it's not uncommon for this group of young people to experience social stigma to have signs and symptoms of depression anxiety even some PTSD difficulty transitioning to adult health care systems because perhaps during their earlier care their care was directed by their parents but now they may have physical and psychological late effects so they need to track their care. They need to understand how perhaps their cardiac function was affected by their treatment but they're not used to having to drive that system and find the right providers who can help them. Sexuality issues relationship issues challenges with identity. Sometimes we see this group of young people after treatment engage in risky health behaviors again almost because they missed that developmental stage of trying on risky behaviors and now they're

25 and it feels like now is the time to do that. It's very interesting and it brings to mind questioned kind of going into my side of the world in online programs would you say and this research show that adolescents and adults that are cancer survivors are more prone to continue their education and in an online environment they may find themselves possibly fitting in better. Well what are the things that we have seen I don't know about the education specifically although it is a really intriguing research and clinical question but we have seen that online support programs have been very important for this group of young people in fact I'm a part of a team of researchers here at UT where we are looking right now at the online communication of AYA's when they're seeking support from each other.

[00:10:47] So there's been a couple incredible online support programs one of which that we're studying is planet cancer that is designed specifically for adolescents and young adults and so they seek support from each other online and we're beginning to try to understand how is the support different similar what are they getting. What helps what doesn't and then how do design programs. Excellent. So what can social workers offer in this area to meet these challenges. That's a good question. I mean I think one being aware of the unique set of challenges and also having being willing to ask about a young person's cancer experience so this is not just for oncology social workers social workers working in any setting to find out if a young person has had some experience with cancer either their own or a family members which is another whole discussion we could have but to be willing to ask the questions so that we can probe a bit and find out is this something that they're struggling with one of the things that my research has shown is that this group of young people again post cancer. Part of what they're doing is struggling with this identity integration. So who am I now. Am I a cancer survivor Am I a person who had cancer. When do I disclose that how do I integrate that. What about if I'm forming a new relationship. When do I let somebody know. You know what. I had cancer and this is how it's affected me psychologically physically. They need social work support to talk through all of those issues and all the meaning making issues that come up.

[00:12:21] They also need social workers to help them identify perhaps other people and that they can connect with because the need to belong is very strong. So being able to get support as a survivor and to increase the relationships that they have that enhance their health and wellbeing are there are some practical implications of this research towards practice policy social work education and even future research. Well I hope so. We always want to research to have practical implications but one of the ways that I've really seen practice influenced by this type of research mine and others I'm a part of a great group of people who are really dedicated to studying and understanding and improving care for this group of young people is that more and more we're seeing specialized clinics crop up for adolescents and young adults so that when they receive their treatment they are neither in the waiting room with all the highlights magazines and Elmo. Nor are they in the waiting room with the AARP magazine that perhaps they're getting treated somewhere in the middle there with a group of providers that is uniquely dedicated to both their medical needs and their psychosocial needs that gets it if you will and that we're also seeing that in survivorship clinics. So there are a lot of programs being developed in this country. I would actually say that internationally some places like England and Australia maybe even a little ahead of us in terms of developing some of these services and so there is an adolescent young adult alliance that has formed that is here in the United States and brings in international folks as well. Well we take all this research and we look together to say how do we improve care.

[00:13:59] And one of the ways is we've learned a specialized clinics support and connection with others who can help being aware that there may be some need for specialized programs to help with school and work reintegration issues of fertility and sexuality and being able to talk about those issues influencing policy so that this group of young people has access to healthcare. The reason that the cure rates are not as well is that this is the group that is the most likely to be uninsured or

underinsured. So there are some real policy implications there and certainly in social work education I am passionate about making sure that we include information about adolescents and young adults with cancer and their families. And so what could be done. Because as you mentioned earlier in the interview at many times the diagnosis isn't really found here. A teenager goes into their doctor saying that they had some pain their leg or their thigh and may not be thought off top their head. Oh I must do some tests to see that there might be something more serious at hand. How do we educate the medical community the health community in being able to try to catch. I would assume that the earlier a diagnosis can be made the higher the survival rate for the teenagers that correct. absolutely. So whenever we can diagnose early or we can treat earlier. And one of the ways I'm a part of a group and I think I'm not alone. There are groups in a variety of settings that are working very hard to educate general practitioners so not just the oncology professionals but the general practitioners who may or may not consider cancer in this young group to raise the awareness of that.

[00:15:36] And what are those survival rates at this point in time. Well survival rates vary tremendously for this group but we do see that it's lower than in the geriatric or in the pediatric setting for yourself. Dr. Jones What's next for you. What are you continue to do in your research. Well next I'm really focused on Intervention Research so now that we understand what these needs are the next step is of course to improve care so working with other teams to say how do we make sure that early on we're addressing all this psychosocial and health promotion aids for this young group. Well I want to thank you Dr. Jones for your time. It was a pleasure. Thank you very much. You have been listening to Dr. Barbara Jones discuss the impact of cancer on the psycho social development of adolescents and young adulthood. Additionally Dr. Jones offered information on the scope of this problem as well as the role of social work in addressing it. This is your host Charles Sims. Please join us again at in social work. Hi I'm Nancy Smith professor and dean of the University at Buffalo School of Social Work. Thanks for listening to our podcast. We look forward to your continued support of the series. For more information about who we are as a school our history our programs and what we do we invite you to visit our Web site at www.socialwork.buffalo.edu.