



Pediatric Cancer

Pediatric Cancer Survivorship

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Welcome to Yale Cancer Answers with doctors Anees Gore and Steven Gore. I am Bruce Barber. Yale Cancer Answers features the latest information on cancer care by welcoming oncologists and specialists who are on the forefront of the battle to fight cancer. This week it is a conversation about pediatric cancer survivorship with Dr. Nina Kadan-Lottick. Dr. Kadan-Lottick is an Associate Professor of Pediatrics and Hematology/Oncology at Yale School of Medicine and Director of the HEROS Clinic for pediatric cancer survivors at Smilow Cancer Hospital. Dr. Gore is a Professor of Internal Medicine and Hematology at Yale and Director of Hematologic Malignancies at Smilow.

Gore It is so wonderful that here in 2018 we talk about pediatric cancer survivorship because I remember when I was a kid, you would hear, "oh! So and so has leukemia," then you would never see the kid again. They drop out of school and that would be that.

Kadan-Lottick In one generation, we have taken childhood cancer from being a uniformly fatal disease to cured in about 85% of children.

Gore 85%? And what percent of that is due to this great progress in leukemia and what percent is in other kinds of cancers?

Kadan-Lottick Leukemia is the most common childhood cancer. It comprises about 30% of childhood cancers, but incredible strides have been made even in brain tumors and in solid tumors of different body parts – kidney tumors and so on. So, we have really seen success all around.

Gore I am always so impressed that the pediatric cancer clinic is right next to my hematology clinic, and I see the kids coming out with their parents and I never see kids looking very unhappy, they always seem like pretty matter of fact and they have got little toys and everything, it seems like they are tolerating whatever is going on there pretty well?

Kadan-Lottick You are a parent, I am a parent, I think that we would never wish this and would do anything to avoid our children having cancer including taking it on ourselves, but having said that, I do think that we have made a lot of progress in understanding how to better care for these children with the idea that they are going to live long healthy lives, that the majority of them will and so, it really starts even during treatment in which we encourage children to be children, we try to do as much therapy outpatient and we encourage them to go to school during therapy whenever they can and there are a lot support services and our social workers liaison with schools during therapy and after therapy so that they are living their full lives.

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Gore That is really amazing. Why don't we start with what survivorship means and what does a survivorship clinic do?

Kadan-Lottick In one way, everyone is a survivor who has had cancer, who is alive and living even if it is during therapy, but when I talk about survivorship, I am specifically talking about the period after therapy and all the decades that follow in how to optimize quality of life. Now that we have made great strides in quantity of life, how do we optimize quality of life after therapy and in terms of typical things like not having chronic health problems or limiting chronic health problems and also psychological functioning and school functioning and just living every aspect of your life as healthy as possible because the truth is that cure must come first, it is the most important. But many therapies have unintended consequences that can occur in the months after therapy ends, the years after therapy ends and even decades after therapy ends.

Gore Tell us what some of those unhappy downstream effects are or the unintended consequences as you put it.

Kadan-Lottick The first thing to know is that many of these unintended consequences can be prevented or made less if we identify them early and start treatment early. Some examples would be that there can be problems with growth or going through puberty, there can be problems with heart function with the heart muscle not functioning as well, there can be problems with early cataracts. It depends entirely on the therapy the child received, what dose and at what age, and sometimes, the sex as well. For example, females who have had chest radiation are at almost 30-fold increased risk of breast cancer, usually occurring after they are 25, and males with chest radiation are not immune to this, but the actual number of cases we see are much less, and then so for these young women, we recommend that they start getting breast MRI screening early in life because when we do that, even if they develop a problem, we catch it when it is very small and can be taken care of with surgery only.

Gore Fortunately there is not a huge number of kids with cancer, but we want to take care of the ones that do.

Kadan-Lottick Fortunately you are right, we only have about 10,000 children diagnosed with cancer, somewhere between actually 6-10,000, depending on what you call a child, under the age of 21 with cancer in our country, each year, but they are living longer and we are increasing our numbers.

Gore Of kids surviving?

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Kadan-Lottick Surviving and they are living past their cancer, so there are an estimated 400,000 childhood cancer survivors in our country right now and the number will keep on increasing thankfully and that means that in the young adult age range about 1 in 300 young adults, are survivors of childhood cancer. And so, if you think about joining a high school class or a college class at UConn, there are going to be a lot of survivors in that group.

Gore I was recently at a board meeting for the National Institutes of Health and one of my younger colleagues whom I have known for a long time reminded me that he was a survivor of Hodgkin's disease, Hodgkin's lymphoma. He pointed to his neck and I looked at him, and he says, "my Hodgkin scar," I had totally forgotten because of course I do not think of him as a Hodgkin's survivor at all. But you just do not know the history of the person next to you.

Kadan-Lottick You do not, and I think one of the other exciting areas of medical research has been being able to understand what problems survivors can develop later in life. It is not a guarantee that they will develop side effects, by the way if they are at increased risk, it just means that they are at increased risk compared to the person next to them that did not have cancer, but it does not mean that they probably will get it. It just means that it is worth giving extra attention to doing what I call super checkups each year rather than a regular health checkup that anyone should have. These patients, depending on what they have, may have extra tests. For some people, I may check an urinalysis every year to make sure their kidneys are functioning well or for another patient I mentioned there are some who had chest radiation, I would do a breast MRI or if there was someone in school age who had brain radiation, I would think very carefully about doing testing for learning problems so that they could be identified and the school could know how to deliver the best education plan for the child. So your colleague or your friend who is a Hodgkin survivor, I do not know about what therapy he got specifically but the things I think about with Hodgkin's patients is there are therapies that make females go into menopause earlier in life at an unpredictable time, so one thing I like to discuss with young women is whether they would want to consider egg harvest if they have not met their life partner and are not ready to start a family so that it is kind of a backup plan. Another thing we talk about is the risk of heart trouble and if they have had chest radiation, you can have early heart attacks, so they can get cared for even if they are only 25 or 30.

Gore Well, if there are really 400,000 survivors of childhood cancers in our population, there cannot be that many docs who have survivorship clinics to follow these people?

Kadan-Lottick And that is a challenge and that is why I am so delighted to be here. I really want to spread the word that after cancer therapy is over, we should rejoice and we should

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celebrate, but please make sure that the survivor is getting the super yearly checkup that they need so that we can prevent problems because this care could be done at a specialty survivor clinic and there is one at Yale, and at centers around us that are excellent and that is one option. Another option is to get a survivorship care plan prepared either by your treating doctor or by a one-time visit to one of these survivorship clinics to be implemented by your local doctor, and in this care plan, it could list specific examples, so every year get these blood tests, get this type of x-ray every 3 years, and it could just be a prescription for what the care should be and it could be delivered anywhere. I want to spread the word because less than 20% of childhood cancer survivors are getting the recommended care and most of it is due to lack of knowledge and I think there a lot of reasons for that lack of knowledge, one of them is that this is an emerging area in medicine and we are still getting our head around living long healthy lives, which is wonderful, and the second is often I think emotionally the door closes when treatment ends in terms of hearing anything more about cancer and it is terrifying and I think that it would be really great to get the message across that this is not necessarily a reason to worry and be anxious so much as being empowered because these things will happen, but why not prevent them from happening or why not make them as insignificant a problem if they must happen. There is a long period for all these conditions in which they are clinically silent, in which they still deserve intervention, but no one knows there is a problem, you do not have body complaints that say there is something wrong, but there could be an intervention to prevent it from progressing. And that is why this yearly what we would surveillance or yearly checkup could make all of the difference, and I just wish we could reframe it that way as a wellness visit rather than a cancer visit.

Gore It makes sense.

Kadan-Lottick I think the third cause is that as oncologists, we really love our patients so much, we really do, we care and that is true of everyone I know and I think it is very hard after someone is finishing therapy to tell them that there is something else they need to do, but I think we should do it while the door is still open, while we still are in close contact and share this for what continuation care should be or what their special checkup should be.

Gore This is a really important topic and I want to take it up again in the second half, but right now we are going to take a short break for a medical minute. Please stay tuned to learn more information about pediatric cancer survivorship with Dr. Nina Kadan-Lottick.

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This is a medical minute about melanoma. While melanoma accounts for only about 4% of skin cancer cases, it causes the most skin cancer deaths. When detected early, however, melanoma is easily treated and highly curable. Clinical trials are currently underway to test innovative new treatments for melanoma. The goal of the specialized programs of research excellence in skin cancer or SPOR Grant is to better understand the biology of skin cancer with a focus on discovering targets that will lead to improved diagnosis and treatment. More information is available at YaleCancerCenter.org. You are listening to Connecticut Public Radio.

Gore Welcome back to Yale Cancer Answers. This is Dr. Steven Gore. I am joined tonight by my guest, Dr. Nina Kadan-Lottick. We were discussing pediatric cancer survivorship. Nina, before the break you were talking about the treating pediatric oncologist, or perhaps a physician from a pediatric cancer survivorship clinic, outlining for the patient and the family kind of the future anticipatory health needs, and I was thinking it is kind of like when you get a new car and your owner's manual tells you, you are supposed to do this at 5000 miles or this at 7000 miles when you are supposed to change the oil and when you are supposed to check the electronics, that kind of thing.

Kadan-Lottick I like that analogy. I think I am going to use it with my patients because that is exactly what it is. It is a roadmap for how to be the healthiest person that you can be through all the life stages and as a pediatrician, I think it is particularly challenging because we take care of our kids when they are little, they often are not able to understand what is going on, even our teens are at a different developmental stage when they may not have a full understanding and yet this knowledge they need to have for how to take care of themselves continues into adulthood, so how do we overcome the challenges of time and distance, and I say time because they go through different developmental stages and have different needs at different times and then I say distance because young people are really mobile and my patients are not necessarily always going to live near me when they may have questions and they will have to find the answers from new providers or even know what questions to ask, so the driver's manual is great because it is always kept in the glove compartment and I have thought of things more simplistic, it is really hard for a piece of paper to travel with someone through life.

Gore Right, what happens if you lose the paper?

Kadan-Lottick I have suggested to people crazy things like keeping it in their freezer.

Gore Or maybe safety deposit box would be a little better.

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Kadan-Lottick But it needs to be handy when you need it.

Gore Well, that is true.

Kadan-Lottick And then we thought about electronic ways, so I have been very excited about the electronic health record as a solution. I think we ought to really be thinking about ways that we can store this type of information in electronic health records in a way that kids can access as adults wherever they are, wherever they move to if there can be basic elements that are always with them for what their personalized health plan needs to be.

Gore Yeah that is a great idea.

Kadan-Lottick And so, we are working on that and other researchers around the country too. But I think the main thing is also to communicate with the family, the parents, how to teach them, how to teach their kids what they need when they grow up. For that to be part of the many responsibilities we have as parents, for these parents to really be able to convey the idea that they have to their kids as they grow up that they need to do certain things to stay healthy. And that includes health behaviors like not smoking, drinking in moderation, and that is good for all of us, but it is really important for someone who had a chemo that affected their liver or kidneys. But it also includes things like be sure to be getting the super checkup, and I want to add one other thing about it, I want to be really clear, not everyone is at risk for everything, so I listed some possible problems that can occur, but I really want to say one of the important things is to also find out just as much about what you are not at risk for as well as what you are at risk for. So, not everyone is at risk for infertility, not everyone is at risk for early menopause, not everyone is at risk for growth problems and it really depends on what you have got or did not get, and as I said the dose and what age you are.

Gore I know that for regular health maintenance issues in adults and young adults and adolescents, talking about weight control, healthy diet, exercise, blood pressure screening, these are difficult to get average people to monitor, so knowing things and acting on them is challenging in and of itself, and I can only imagine, maybe I am wrong, but I have to imagine that the childhood cancer experience is as nice as you guys can make it for them, but it's still got to be scary and traumatic, and I would think that a lot of adolescents after that and young adults, they probably do not want to think about it, they just want to be healthy now.

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Kadan-Lottick They do. I think a lot of the interventions that we work will be the ones that are focused on treatment period and normalize the message for diet and exercise. We are really trying to work on encouraging lots of fruits and vegetables, lean meat from the time of diagnosis and this is hard because it is really tempting to give a child treats.

Gore Ice cream.

Kadan-Lottick I know it is very hard to say no and to set limits, but we are really trying harder to educate our families about the benefits of it. Those interventions improve outcome during therapy and that has been shown and they are very important after therapy. So, trying to make those health behaviors normal earlier on I think helps. And as I said, there is a lot more bang for your buck, we should all exercise, we should all eat healthy, but for example, for someone who got a type of chemotherapy called anthracyclines that causes the heart muscle to be weak over time, we have demonstrated that optimizing your other cardiac risk factors makes the effect of that chemo smaller. So, you take two people who have got the same dose, but the person who subsequently after therapy has lower lipids, does not develop insulin resistance, has a body mass index in the optimal range, is not obese, etc.

Gore Does not smoke.

Kadan-Lottick Does not smoke and has hypertension or whose hypertension was screened and is now treated, they do better. So, these patients, these survivors have some power to change their whole risk profile by these health behaviors and we try to teach that to our patients. We try to teach it to parents and we find that what helps is when the whole family takes it on for themselves and it is not just for the patient, but it becomes a lifestyle change for the whole family. So, we are trying to think about how to do that and we appreciate that the patient is not in isolation and their child is part of their whole family.

Gore Yeah. That brings me to, what about siblings? I have to imagine it is hard for siblings, this child is involved with the cancer, their sibling is getting so much attention from the parents, so much of the family's resources and needs are focused on that.

Kadan-Lottick And also guilt, that is another issue, that they do not have cancer.

Gore Now again this whole thing not to eat ice cream on top of it?

Kadan-Lottick Well, I think ice cream is very good for you in moderation, but I think that the strongest message we can give for everyone's wellness is to normalize family life and to

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set the usual limits. I think actually there is more anxiety and fear and adjustment problems when parents are not setting those limits, and I also want to appreciate that a cancer diagnosis impacts the whole family --the siblings, the parents, other family members, and when we look at emotional health after cancer treatment, rates of anxiety and depression are actually similar to the general population.

Gore Is that right?

Kadan-Lottick It is. Now, those who are in distress definitely should get and deserve sensitive and excellent care, but when you actually look at rates of problems, it is highest in mothers and fathers. Mothers and fathers have high rates of anxiety and depression and posttraumatic stress disorder in the years and even decades after because I think as a parent, there is nothing more life threatening than to have something happen to your child and then similarly we are seeing high rates of anxiety and depression in siblings, and just because therapy ended, it is important to take good care of yourself in all of these ways afterwards and realizing as we talked about unintended consequences of the therapy and that it does not necessarily stop on the date that therapy stops.

Gore Is there a higher rate of failure of marriage among parents who are dealing with a child who has cancer?

Kadan-Lottick Yes, that has been demonstrated. There is a higher rate of divorce, there is a higher rate of loss of income definitely during the treatment period, but that can persist.

Gore One of the parents has to give up their job a lot of times.

Kadan-Lottick One of the parents has to give their job or even if they do not give up their job, or even if one parent gives up the job, the other parent may give up other opportunities and goes on a different kind of job trajectory because of the period in which everything had to stop.

Gore Also just how partners support each other right. I mean, people may have certain expectations of their partner who may be responding to the crisis in a different way and it really is a terrible stressor I would imagine.

Kadan-Lottick It is and our social workers spend a lot of time with our parents to help them cope through the experience, but I do really encourage parents to get that care. I am not so worried about the treatment or therapy, as hard as it is, I'm not being insensitive but just saying we have already put into place a lot of resources that are available and a lot of safety nets to help families and we monitor them very closely on therapy, but what often happens, and families tell me this, parents tell me this, is that when therapy

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ends, those things end and I would think that an important part of survivorship is recognizing taking care of your family, taking care of your relationship, recognizing that having a child with cancer is not just an episode and it is over, but that it is important to look after your emotional well being as well and that can persist in the years and decades after. I looked at my own survivor clinic and about 40% of adult patients come with their mothers still.

Gore How long do patients continue to see you?

Kadan-Lottick Different survivor clinics have different models according to how they are set up. In my clinic, I see everyone as long as they want to see me. So, they are diagnosed under the age of 21 enter our clinic, but they can see us as long as they want and we do a consult, I am not doing all of their care and I am not qualified to do all their care, but I screen for complications from their previous treatment and my oldest patient to-date is 69 years old.

Gore Oh! My goodness!

Kadan-Lottick But she is getting great care and she is plugged into all of her wellness checkups for the year. And as part of that, I would go back with the families, I would like to see the family, the parents also taking care of themselves afterwards because it has been said in a short way that it is not just the quantity of life, but it is the quality of life that matters.

Gore Can I ask what your 69-year-old patient was treated for?

Kadan-Lottick Actually she was treated for Hodgkin lymphoma and she is doing very well, yes it was decades ago that she was treated as a teen.

Gore That has got to make everybody feel pretty good.

Kadan-Lottick It does. I find my work a very positive and optimistic career, I really love that and I love seeing how people go through different life stages, I have some patients that I have had on therapy through college and then hearing about their first job and then their engagement and their children, it is a lovely thing and this is a great boon that we have in pediatric oncology that we have diseases that we have found the right answers for.

Gore Yeah, it is amazing and wonderful.

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Kadan-Lottick We still have work to do by the way, 85% is not good enough, we want to do better.

Dr. Nina Kadan-Lottick is an Associate Professor of Pediatrics and Hematology/Oncology at Yale School of Medicine and Director of the HEROS Clinic for pediatric cancer survivors at Smilow Cancer Hospital. If you have questions, the address is canceranswers@yale.edu and past editions of the program are available in audio and written form at YaleCancerCenter.org. I am Bruce Barber, reminding you to tune in each week to learn more about the fight against cancer here on Connecticut Public Radio.