The HEROS Clinic for Pediatric Cancer Survivors

Guest Expert: Nina Kadan-Lottick, MD

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Welcome to Yale Cancer Center Answers with Dr. Ed Chu and Dr. Francine Foss, I am Bruce Barber. Dr. Chu is Deputy Director and Chief of Medical Oncology at Yale Cancer Center and Dr. Foss is a Professor of Medical Oncology and Dermatology specializing in the treatment of lymphomas. If you would like to join the conversation, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1-888-234-4YCC. This evening Ed is joined by Dr. Nina Kadan-Lottick. Dr. Kadan-Lottick is an Associate Professor of Pediatrics and Pediatric Oncology at Yale School of Medicine and Medical Director of HEROS clinic at Yale Cancer Center. Here is Ed Chu.

Chu You are a pediatric oncologist who studies pediatric cancer and your special area of interest is pediatric cancer survivorship. One thing we like to do is to introduce our guest and have them explain how they got interested in the field that they are in, so maybe you can start off by telling us how you got interested in studying pediatric cancers and then how you got interested and very deeply involved in survivorship.

Kadan-Lottick I knew I wanted to be a pediatric oncologist even before I knew I wanted to be pediatrician. In medical school, I had the privilege of getting to know several children going through cancer treatment very well, and their families, and I was so excited about the field because we were developing so many new therapies that were making a difference and it was the cusp of when cancer treatment went from about 50% survival rates to the majority of kids surviving their disease, and I was very excited about being able to help these children. Later, while I was in training for pediatric oncology, as I was caring for patients and I observed that my children undergoing therapy for leukemia were experiencing fractures on therapy and that made me do a lot of reading and I learned that steroids and methotrexate can cause decreased bone density. That was a very important thing for an oncologist to be aware of because there is something to be done, and because I was aware of that, I started encouraging my patients during therapy to take calcium supplements and to do more weight bearing exercises, and from that I wanted to learn more about ways that we can help children stay well once we rid them of their cancer. We’re not just in this field to cure someone today, or six months from now, we are here to give them healthy lives for the future.

Chu One thing that is important to emphasize to our listeners is as you said, for pediatric cancers, now the expectation is that the vast majority of the patients will be cured of their disease, which really is very different when I think about what we see in my field, in the treatment of adult cancers.

Kadan-Lottick It is, I think many people would be surprised to know that about 82% of all childhood cancers are cured long term, and that even some of the cancers that we think of as particularly ominous, like brain cancer, 2/3 of them are entirely cured and for the most common type, acute lymphoblastic leukemia, survival rates are above 90%.

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Chu  Just curious, this lymphoblastic leukemia, what fraction of these cancer patients that you see in your clinical practice makes up the total proportion of pediatric patients?

Kadan-Lottick About 25% of children with cancer will have acute lymphoblastic leukemia, and the majority of those will have the kind that is very curable and that we are seeing over 90% cure rates.

Chu  What are some of the other pediatric cancers that we can now cure, or you folks can now cure?

Kadan-Lottick We have also done very well with brain tumors now that we have better imaging techniques and our neurosurgery colleagues have more sophisticated techniques to do surgery and we have certain chemotherapy we add after surgery. We have also done very well with the solid tumors including Wilms' tumor, which is over 90% curable. Most recently in neuroblastoma we have newly developed antibody therapy which even cures the advanced stage neuroblastomas. So those are the ones that we have made incredible strides in recently.

Chu  As you say, more than 80% of these patients will be cured. How do you define a pediatric cancer survivor?

Kadan-Lottick The government, NIH, and the National Cancer Institute would describe it very broadly as any individual with childhood cancer who is living from the point of diagnosis. I actually have a working definition that’s a little different because I think of it as the care of the long-term health and well being of a patient. Some of that care does begin during the treatment period and planning for the future, but I really want to distinguish this from the type of care managing day to day symptoms like nausea, and fatigue, and I also want to distinguish this from the field of deciding what the best therapy initially for the cancer is, except to give the least toxic possible so that later in life there are the least problems. Cancer survivorship as a field is devoted to doing all the health measures that we can to improve health now and into the future.

Chu  I know for the definition of adult cancer survivors, that definition is pretty broad and includes not only the patient, but the loved ones and the caregivers, close family friends. I am just curious, is that the same kind of broad definition for a pediatric cancer survivors?

Kadan-Lottick Absolutely, because every one is affected by the cancer diagnosis, everyone who cares about the child, and parents are very intimately involved with their children and a lot of our care is focused at helping parents take care of themselves so they help their child do well. A very practical example of an issue that comes up during therapy that is important later on is the kind of care we give around painful procedures. We have learned that parents get very agitated, even more so than the children, and it is understandable, and if you have kids you know. Around spinal taps and blood draws, we realize that if we can do better in terms of making the child comfortable,
prenatal anxiety decreases and later there is improved long term outcomes for the child because the parent is able to more relaxed, supportive, and not so vigilant after the child has completed therapy. Thus the child can really blossom and not be affected by greater tension by the parents about the other shoe dropping or the anxiety that can persist in parents.

Chu Can you give a sense of magnitude of how many pediatric cancer survivors there are?

Kadan-Lottick It is difficult to estimate because there is not a US census of them, though I wish there were because I’d like them to stay in follow-up, but we have tried to make a very good estimate by contacting the different sites that care for children with cancer and we estimate that there are probably around 270,000 childhood cancer survivors, but because the greatest strides have occurred most recently, that really translates to about one in 500 young adults between the ages of 20 and 39. For example, at a large high school there will be two or three cancers survivors, at a university there will be several childhood cancer survivors and there are many that are part of our workforce who need ongoing care.

Chu You are the Medical Director for the HEROS clinic for pediatric cancer survivors at Yale Cancer Center, let’s talk a little bit about the clinic. How did the name HEROS come about and when was this clinic first established?

Kadan-Lottick I started this clinic when I was recruited to Yale in 2003 to start the clinic and to start a survivorship program. The name HEROS started because that is how we think of our patients and their family members, so we knew we wanted to use the word HEROS, that is the word that came in my mind and we made it work. We worked backward and thought of the words that HEROSS could stand for, which is Heath Education, Research, Outcomes, and Survivors.

Chu HEROS is really a great term for what you are trying to accomplish in your clinic.

Kadan-Lottick Thanks.

Chu Who makes up the clinic, who are the other members of your team?

Kadan-Lottick On our team, we have a nurse coordinator, Tonetta Christie, we have a psychologist Lyn Balsamo. There is another oncologist that works with me, Dr. M. J. Hogan, we have a social worker, Connie Nicolosi. We also work closely with an endocrinologist Dr. Stu Weinzimer and with a couple of internists in the community including Dr. Steve Brodner in terms of reviewing our patients that are coming to the clinic, deciding what to focus on in the clinic in terms of what therapy they have had before and what we should screen for and what health topics we should discuss and then reviewing and interpreting results of the actual clinic evaluation.

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Chu Does every patient who comes to your clinic see each of these individual members of the team?

Kadan-Lottick For every patient there is a visit with an oncologist or doctor who goes over the history and we do a physical with a nurse to go over health education, including how to optimize health behaviors like nutrition and diet, exercise, how to do breast self exams, and our nurse psychologist to screen for learning problems and for emotional health. Then the endocrinologist, who is not physically in the clinic, will review all the findings before and after so that we only send people out to see the endocrinologist if they need to. A lot of kids need endocrine testing. By the way, the most common type of complication is hormonal. The social worker is also on a need basis; certain individuals have trouble getting health insurance or need help with getting school services.

Chu What are the main age groups of patients that you typically see in your clinic?

Kadan-Lottick Patients range from age 2 to about 57. They are childhood cancer survivors and they need specialized care and we are able to provide it. I will be honest, I am a pediatrician, so we’re good at surveillance and knowing what we should be watching for, but if we do find problems, I handle that by talking with their internist and the key to this clinic is we function as a consult clinic, as a specialty clinic. We want to be an adjunct to excellent primary care and excellent oncology care, so a key part of what we do is that we summarize the treatment history from the medical records. Tonetta, our nurse, does this, she puts it all on one half page, all of the diagnosis information, the treatment exposure, so it is in one place and then on the same page we have a problem list of all of the issues, medical issues, or psychosocial issues, that have occurred related to the past cancer or cancer treatment so that any one taking care of that patient, whether it is an ER physician or primary care doctor, can find in one place every thing that is needed, because often these patients have very complicated histories, and childhood cancer survivors as adults are not going to be able to report what they had accurately. It is too complicated for anyone to remember in development, so they would not be in a position to be able to make notes themselves. We have actually done a study that was published in JAMA a few years ago that showed that the adult survivors with childhood cancer are not able to report well even what their diagnosis was, the name of the diagnosis, never mind what therapy they had. We think of this as a passport, so to speak, that they have as a key to getting good care no matter who they see, and that includes the 57 year old. We provide all the information to our internist and we give recommendations about other surveillance things that should be done and problems identified, some of the things we have identified include second cancers, high cholesterol, and heart failure. We then discuss with the internist how to follow-up the therapy.

Chu Why don’t we go ahead and take a short break for a medical minute. Maybe on the other side of the break we can talk a little bit about some of the short term and long term consequences and or

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potential complications of surviving pediatric cancers. Please stay tuned to learn more information about pediatric survivorship with my guest, Dr. Nina Kadan-Lottick from Yale Cancer Center.

Medical Minute

It is estimated that nearly 20,000 men in the US will be diagnosed with prostate cancer this year and over 2000 new cases will be diagnosed in Connecticut alone. One in six American men will develop prostate cancer in the course of their lifetime. Major advances and the detection and treatment of prostate cancer have dramatically decreased the number of men who die from this disease. Screening for prostate cancer can be performed quickly and easily in a physician’s office using two simple tests; a physical exam and a blood test. Clinical trials are currently underway at federally designated comprehensive cancer centers like the one at Yale to test innovative new treatments for prostate cancer. The da Vinci Surgical System is an option available for patients at Yale. It uses three dimensional imaging to enable a surgeon to perform a prostatectomy without the need for a large incision. This has been a medical minute and more information is available at yalecancercenter.org. You are listening to the WNPR Health Forum on the Connecticut Public Radio Network.

Chu Welcome back to Yale Cancer Center Answers. This is Dr. Ed Chu and this evening I am joined by my good friend and colleague Dr. Nina Kadan-Lottick who is Medical Director of the HEROS clinic at Yale Cancer Center. This evening we are discussing the important topic of pediatric survivorship. Before the break Nina, we were talking a little about the nuts and bolts of your HEROS clinic, which really again is just a fabulous clinical service that you are providing for pediatric cancer survivors, and I thought we could now focus a little bit more detail on some of the short term and long term consequences that pediatric cancer survivors have to deal with.

Kadan-Lottick Absolutely, so first of all the good news is that these children are surviving to adulthood and now we are even seeing them grow old, and that is wonderful, but what we have learned is that the therapies can come at a cost and about two thirds of childhood cancer survivors will have at least one moderate to severe medical or psychological complication of their previous cancer therapy, and the most common ones are hormonal, with hormonal deficiencies, growth problems, and problems with fertility, but also we see problems with bone density and osteoporosis and increased risk of second cancers. The overall risk is low, meaning most people, most survivors will not get it, but the risk is elevated over the general population and then something I am particularly interested in is learning problems, because chemotherapy, as well as radiation, can effect processing of information including memory and how fast we can process information.

Chu I’d imagine the sequelae will depend in large part on the specific treatment that a patient received; chemotherapy, radiation therapy, or perhaps a combination of chemotherapy and radiation therapy.

19:16 into mp3 file http://yalecancercenter.org/podcast/july1110-cancer-answers-kadan-lottick.mp3
Kadan-Lottick I am glad you pointed that you, that is absolutely right and a key part of the care we provide is just sharing with individuals what they are at increased risk for, and maybe just as importantly, what they do not have to worry about, because often there are misconceptions in people’s mind and they can’t let go of some of the worries. We help them let go of some of the worries, and that is why the treatment summary is so important because it is the specific treatments and the doses that they got that indicate what problems they are at increased risk for and thus, what type of screening tests should be done, if any. There are certain groups of patients that are going to be at risk for almost nothing, and those would include some of the lower stage solid tumor patients, the low risk acute lymphoblastic leukemia patients, and then in general, the patients that receive both chemotherapy and radiation therapy, are at the highest risk for the most problems.

Chu Is the development of some of these complications, secondary effects of the treatment, dependent upon the age at which the patient is diagnosed and treated?

Kadan-Lottick It is and again it really depends on the specific treatment pertaining to increased risk whether you are older or younger. For example, females that are treated at older ages like post pubertal ages, are at increased risk for infertility, but younger ages of a chemotherapy called Adriamycin, puts you at greater risk of heart failure that you do not experience if you are older. Also, being younger puts you at increased risk of learning problems with chemotherapy and radiation. It depends on the treatment exposure and again, that can be just as telling as to what you are at risk as well as reassuring for what you are not at risk for.

Chu Are there any effective strategies to try to prevent some of these, what sound like pretty serious complications, from ever occurring?

Kadan-Lottick There are, and it’s interesting. It goes back to what the definition of a survivor is. We are learning that some of the things that can prevent problems need to be done during therapy. For example, Vincristine causes neuropathy or weakness in the nerves that in turn cause weakness in the muscles and we have learned that if we have patients do certain exercises with the physical therapist during therapy, they are less likely to have weakness later on. Some of the things are simple, like sperm banking for post pubertal boys before chemotherapy, which will then be an insurance policy against infertility later. We are doing research with chemoprotectants, drugs that can be given at the same time that can help protect the heart against heart failure problems and the mind against learning problems, and those are still in research.

Chu Now, if you were to identify any of these downstream consequences of therapy, would you be seeing these patients in your HEROS clinic, or would the care really be transferred to the primary care internist, the pediatrician, or the adult internist for individuals older than say 20 years of age?
We see these patients yearly and we see ourselves as in the role of coordinator of care and keeper of all the information so that all the elements of care are addressed. We will make all the appropriate referrals and I give a comprehensive letter to all the doctors. I really encourage patients to give me all the possible individuals in care with the patient and I also pick up the phone and we have an ongoing discussion. I believe strongly that we need a wellness model, and what is the best wellness model but an individual being cared for by their primary care physician? Primary care physicians I think are the ones best suited for the long run and really need to know all the information. I also think it is a better model because I do not think we need to give the message to patients that they are sick and need to come to a cancer center more frequently, that gives the wrong message and I do not think they need to hear that message.

The Connecticut Challenge is a foundation in Connecticut specifically to promote survivorship in Connecticut and was founded by Jeff Keith who is a childhood cancer survivor of osteosarcoma who ran all the way across the country. Now that he is more successful and older he wants to do all he can to promote wellness and survivorship for other survivor so Jeff founded the Connecticut Challenge along with his friends, including John Ragland, and they have been a major supporter of the HEROS clinic and have been able to provide extras like having a neuropsychologist in clinic and being able to do some of our pilot research studies to see how we can help future survivors. In fact, they are having their annual fundraiser on July 24 in Fairfield and their website is ctchallenge.org for anyone who wants to ride in the bike event or volunteer. It is a really fun day and I particularly find it a very optimistic day because survivors and loved ones as well as just a lot of people in the community come together to support them for a great cause.
Kadan-Lottick Most recently I have been very interested in knowing what elements of leukemia therapy most influence late effects including learning problems and I just published a couple studies that showed that the form of steroid dexamethasone, or prednisone, does not influence the type of learning problems, and this has translated back into the frontline leukemia trial. I am very excited to say, I am also a member of the National Leukemia Community that decides the leukemia trials, that this is going to be the first time that the randomized study is going to see if we can preserve cure rates and dial-down therapy.

Chu Very interesting.

Kadan-Lottick It is very exciting. Some other things we are doing are looking at inherited factors that influence how you react to chemotherapy, so we can predict who is going to have more trouble with chemotherapy agents, and that is an ongoing study and we are hoping to have some answers soon, that can translate to how we treat patient’s upfront and identifying who may need more tailored therapy with less or more chemotherapy so that we can mitigate the late side effects that patients have.

Chu In the few seconds we have left, for our listeners out there who want to learn more about the HEROS clinic and about pediatric cancer survivorship, can you give us a website and a phone number?

Kadan-Lottick Absolutely, if any one would like to be seen as a childhood cancer survivor, please call (203) 785-4640 and also you can see us on the Yale Cancer Center website. There is a link to the HEROS clinic and you can learn more.

Chu Nina, it has been great as always to have you on the show. I think it does really provide us a nice overview of pediatric cancer survivorship and we look forward to having you back on a future show.

Kadan-Lottick Thank you so much.

Chu Until next week, this is Dr. Ed Chu from Yale Cancer Center wishing you a safe and healthy week.

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