

Yale CANCER CENTER *answers*

WNPR Connecticut Public Radio



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Diagnosing Childhood Cancers

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Welcome to Yale Cancer Center Answers with doctors Francine Foss and Anees Chagpar. Dr. Foss is a Professor of Medical Oncology and Dermatology, specializing in the treatment of lymphomas. Dr. Chagpar is Associate Professor of Surgical Oncology and Director of the Breast Center at Smilow Cancer Hospital at Yale-New Haven. 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 week, doctor Chagpar is joined by Dr. Gary Kupfer. Dr. Kupfer is Professor of Pediatrics in Hematology, Oncology and of Pathology at the Yale School of Medicine. Here is Anees Chagpar.

Chagpar Why don't we start off by having you tell us a little bit about what you do?

Kupfer I love taking care of patients with blood diseases and cancer, but I also enjoy doing all kinds of other things including research, teaching being involved in all the enhanced services that go into taking care of kids with cancer and blood diseases here at Yale.

Chagpar Tell us a bit about what it takes to look after kids with cancer, because when we think about cancer, for the most part, we think about adults with cancer.

Kupfer We have really tried to build a program here at Yale that addresses all of the unique difficulties and challenges that children have when they are diagnosed with cancer, as you might expect. Although some of the diseases have similarities to those in adults, children face a whole lot of other unique challenges, and in fact, ones that extend out to the families, other relatives, classmates as well as neighbors in the community, and it is really entails more than just simply hanging the chemotherapy, it is seeing to all their unique requirements such as entry back into school, the increased risk of mental health challenges that our patients face, and that includes the increased incidence within the families, and the extended family as well.

Chagpar I think that it is so interesting that you mention that because when we think about cancer we really do think about treating the cancer, but it seems to me that you take a broad view when it is a kid with cancer, it is not just treating the kid with cancer or the cancer in the kid, but treating everything about that child, and how that child is in their family, in their neighbourhood, in their school, that is remarkable.

Kupfer As you might expect, patients see their lives as not simply spent in clinic getting their chemotherapy or getting their blood products or getting their antibiotics, it is really how they reengage with their friends after they embarked on their chemotherapy. How do they behave when they go to back school? When they lose their hair? How do their classmates treat them? There is a long list of things these kids have to face and I am not just talking about little kids, we are talking about big kids too, and our adolescents and young adults that we take care of within our program face an even different set of challenges than the little kids for whom we more typically think of when we think about kids with cancer.

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- Chagpar Let's start there. It would seem to me that you would need a whole host of different types of healthcare providers to look after all of these different facets, more than just doctors and nurses hanging the chemotherapy, as you say. Tell u about the multidisciplinary approach in pediatric oncology?
- Kupfer It really starts with the patient and the family themselves, we actually incorporate our families very much into the care of our patients from the beginning because truth be known, when patients go home from clinic or go home from the hospital, we depend on the parents or the extended family members to be our eyes and ears so that we can take better care of those kids. So it really starts with them and we incorporate the family within our treatment program and help them understand what we are going to do, the parameters of how we care for patients when they do go home, and through every phase of encounters with the patients, doctors, nurses, social workers, psychologist, psychiatrist, educational specialists, we're all part of this team that is really focused on seeing to the needs that encompass the entire child at every developmental stage of life which really goes from infancy all the way to young adulthood within our patient population.
- Chagpar That is remarkable, and I can imagine that with all of this support you build a wonderful infrastructure to take care of kids with cancer regardless of their age, but also you would need that infrastructure to be supportive of these families because as you say, they are integral parts of the treatment team and they would likely need a lot of support too. What is it like being a parent with a kid with cancer?
- Kupfer I think it is that comprehensive view of things that is really critical for their care. Not to downplay what it is like to be an adult with cancer, but I would daresay that many adults go through their day without anyone else knowing what they are going through. I think that is almost impossible when you are a child, because the effects of a child being diagnosed with cancer permeates exponentially throughout the family, throughout the community and so it becomes something that effects everybody within the community. We had a patient recently who had a community get together in West Haven and the outpouring of love and support for that family was just tremendous. I attended with my wife and it was a truly remarkable event for that girl and for her family to be supported and be nurtured by the entire community and I think that is really emblematic of what is like to be a child with cancer. The entire community really feels it and so I think for that reason alone it is so important for us to be comprehensive in our approach towards a child diagnosed with cancer, there are just so many needs that are not entirely evident just simply based on an account of the diagnosis being made on paper. There are so many other things which really need to be addressed so that that child can be functional, that child can continue to develop in a normal way so that, from our point of view, hopefully that child will grow up to one day be a fully functioning and contributing member of our society.

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- Chagpar For our audience, not in the studio with me, Gary is sitting here beaming just at the thought of what these kids can grow up to be and it is remarkable. Certainly the outpouring of support and the potential of these kids to grow up to be healthy, happy, functioning people despite having gotten over a diagnosis like cancer must be incredibly rewarding, but I can imagine it must be challenging to look a child in the eye every day that has cancer. Tell us about what that is like and what brought you to pediatric oncology?
- Kupfer It is sort of a long story about how I got into this business, and it started out with a desire to marry the investigational side, the research side, with the care side. I was always interested in science and I went to work for a medical oncologist when I was in college, but I was always the one on the floor playing with the kids and that was what attracted me most to pediatrics, so to me this was a perfect marriage, so to speak, of what I wanted to be professionally, as well as what I always enjoyed from the days when I was a little kid myself. This was something that was natural for me. But beyond that, I think that what motivates us is to really help these kids along to say that they are cured, but also that they have the best quality of life that we can achieve for them. As you rightly point out, more and more of these children have survived to adulthood and become contributing members of society, but on the other hand because of that success we have been able to focus more and more on what that success mean for that patient, for that survivor, if you will, and that is a term we use all the time around here and rightly so because we have more and more of them and because we have more and more of them we have to start paying attention to what that quality of life really means, and so I think that our focus has rightly turned now in a lot of our disease areas, and in pediatrics, it is a very different situation, while only 15,000 to 20,000 children a year get cancer in this country as opposed to the roughly one million adults. We take care of many different diseases within that umbrella of 15,000 to 20,000. There are many diseases in which children have done exceedingly well and we are achieving survival rates of 90% or more. But there are many for which there are still many challenges but because children are achieving these incredible cure rates of 90% or more, we have the ability to then focus on how does that quality of life look later on? How can we make their survivorship, so to speak, look as good as possible in future?
- Chagpar That is fantastic. Let us turn to those 15,000 to 20,000 and as you say it is kind of potpourri of different kinds of cancers and different kinds of diseases some that do remarkably well and some not so well. What is the most common pediatric cancer that you see?
- Kupfer The most common pediatric cancer is a specific type of leukemia called ALL, or acute lymphoblastic leukemia, and that is about 25% of our patients, and within that particular group of patients we are achieving, on average, about 85% longterm survival for those kids, and so ALL really represents a poster child for our field where we have achieved just incredible success. In fact, if we go back to 1948, which was the dawn of chemotherapy in pediatric oncology, if you were diagnosed with ALL you would have an absolute survival rate of 0%. So not one child with

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ALL survived the diagnosis in 1948 and it is really the combination of one clinical trial after the other within pediatric oncology, mostly through the cooperation of multiple groups across the country coming together for this common purpose, which has enabled us to push that survival curve forward, up and up over the decades pushing the envelope in order to achieve what is currently about 85% long term survival. Clearly it is not where we want to be, we would only be happy with 100% of course and 100% with an absolute wonderful quality of life, but with that number having been achieved, there is an amazing focus that has been placed upon what that quality of life looks like. I want to mention that here at Yale we have an incredible clinic focused on pediatric survivorship which ironically the majority consist of adults because these are adults who made it out of childhood and who are coming back to the clinic for a long-term survivorship focus.

Chagpar That is absolutely fantastic. We are going to pick up on the whole story of clinical trials and survivorship right after we take a break for our medical minute. Please stay tuned to learn more information about pediatric oncology with our guest Dr. Gary Kupfer.

*Medical
Minute*

There are over 12 million cancer survivors in the US right now and the numbers keep growing. Completing treatment for cancer is a very exciting milestone, but cancer and its treatment can be a life changing experience. The return to normal activities and relationships may be difficult and cancer survivors may face other long term side effects of cancer including heart problems, osteoporosis, fertility issues and an increased risk of second cancers. Resources for cancer survivors are available at federally designated comprehensive cancer centers like the one at Yale Cancer Center to keep cancer survivors well and focused on healthy living. This has been a medical minute brought to you as a public service by Yale Cancer Center. More information is available yalecancercenter.org. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.

Kupfer First what I want to mention is that clinical trials and clinical oncology really got their start in pediatric oncology. When you go way back to 1948, as a I mentioned before, that was the dawn of using rational use chemotherapy, and it was in pediatric oncology pioneered by Dr. Sidney Farber, whose name is fairly familiar, but what has happened because of this 15,000 to 20,000 number which although it sounds like a big number perhaps to those of us who work in the field, those are relatively small numbers, it means that from a statistical point of view, we really have to get together with other people, with other institutions around the country and that is what we do, we participate very actively with the Children's Oncology Group in order to provide a whole platter of different clinical trials, each one geared for a specific diagnosis, so here at Yale we have over 50 different clinical trials available for the treatment of different cancers and for the study of increased measures such as increased quality of life as well. So we really have to get together with our sister institutions in order to treat patients exactly the same with an exact menu of different

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chemotherapy, and radiation therapy and surgical options, and we can then pool our data together with our other sister institutions and therefore advance the cause of therapy for each individual disease. Because of this relatively small number, some of the diseases that we deal with only have perhaps a couple of dozen children a year being diagnosed across the nation. So because of that, we have to put together our patients with our other cooperating institutions and we have maintained all of these clinical trials for the betterment of our patients because ultimately these clinical trials represent the latest and best research within each different disease group, so there is not going to be any other cutting edge therapy available for a particular patient than what would be provided through a clinical trial.

Chagpar I often tell my patients, and this is true at least in the adult population and I suspect in kids as well, that the people who participate in clinical trials tend to do better than people who do not participate in clinical trials simply because as you say, we are always comparing standard of care to what we think is better, the next cutting edge therapy. Is that true in kids as well?

Kupfer I think that is absolutely true and it is true for a couple of reasons. Number one, every clinical trial represents ultimately the latest and best research so it is based on every clinical trial that has come before. These clinical trials are actually formulated by national committees in which many of us here at Yale happen to participate, such as the Hodgkin's Lymphoma Committee which I am a part of, and we contribute intellectually as well as sweat equity in order to formulate these various clinical trials. So yes, I really do believe that better care comes from the fact that in pediatric oncology we are a relatively small group, we know each other. We think nothing of picking up the phone or writing an email to our colleagues throughout the country because we work with them several times a year in working meetings to formulate these clinical trials and almost everybody within our group here at Yale is actually a national participating member of the cooperative group.

Chagpar Let's talk a little bit about how kids participate in clinical trials, for an adult you talk to your patient about a clinical trial, you explain the risks and benefits, they sign a consent form and away you go. I would anticipate that for children it is a little bit more complicated. Can you talk a little bit about the ethics and the technical details of participating in a clinical trial for children?

Parker It is interesting because we have to be very age appropriate. We are actually duty bound, ethically as well to explain what we are doing to our patients in a developmentally appropriate way. We have patients who are 18 and older because we take care of young adults. They are fully in charge of their own care and being placed on a clinical trial. For patients down to the age of 13, they are actually required to sign an assent as we call it rather than a consent which is what their parents would sign, but they are required to sign that assent in order to allow themselves to go on a clinical trial and then there is another document for kids down to the age of 8 to look at with us. So we do actually try to explain all of this to children in a developmentally appropriate way, but beyond that,

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we really are champions for clinical trials here because as you mentioned, we believe passionately that our patients do better by being placed on a trial, but also I think in a way we do owe it to those kids who came before, and who were treated on clinical trials before this in order to push the envelope further and to help future generations do better and in fact because of our numbers, pediatric oncology is not treated on a street corner or in a private office. Typically, we are based at academic institutions because most of us who are in this field recognize that we have to treat these kids with academic precision and academic rigor so that we learn and continue to improve the outcomes for all of these children.

Chagpar It would seem to me that in large academic institutions you can really focus on each disease area in a more comprehensive way. Is that right?

Kupfer Absolutely, and one of things we have done here at Yale in recent years is move to that comprehensive model where we focus on specific disease groups. In fact, each day of the week we have a different disease group or different comprehensive clinic that focuses on one aspect of pediatric oncology. Monday afternoon we have our pediatric survivorship clinic, Tuesday we have our coagulation and bleeding disorder clinic, Wednesday's are our brain tumor clinic and so on, so we have realized that patients with these subsets of diseases really have profound needs that are out of proportion to what might generally be had in a regular pediatric oncology clinic. For example, we can talk about our brain tumor clinic, brain tumor patients in particular have great challenges with developmental issues, endocrine issues and of course long term fertility, growth and development and we really try to bring together all the expertise within that particular clinic. We have our neurosurgeons working side by side with our neuro-oncologist. We have our social workers, our psychologists, and we refer them to our endocrinologist who specializes in our particular patient population so they can have all their needs addressed and have a better outcome as a result.

Chagpar I can imagine that that is a complicated process with so many moving parts that you really do need this big multidisciplinary team that really puts all of the minds together to focus on the patient.

Kupfer We talk about how electronically the world is connected now, but I would argue that there is still no substitute for the physical presence of all of these expertise in one place, at one time, with our patient before us, and I think that has huge advantages and that is the kind of clinical environment we have created here at Yale in order to provide our patients the opportunity to be cured and for that care to be at the highest quality.

Chagpar You have mentioned the word cure a couple of times, and I know that many of the people in our audience are sitting there wondering, do you really think that cancer in kids has the potential for cure?

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Kupfer I do not think that any of us, and I am including you in this, would be in this business if we did not passionately believe that. And I think that ultimately we will get there, but I think that pediatric oncology is symbolic of the great difficulty we have had in cancer, and that is that cancer is not just one disease, it is many diseases, and that is part and parcel to what goes on in pediatric oncology and many diseases are more common than others and even within the disease group I mentioned, ALL leukemia, the common leukemia we were talking about earlier, there are many different subgroups of that. Why does one child survive and one does not survive? That is not entirely clear-cut even in the year 2013, and I think those are the great challenges that are before us. We move through our careers, and in the careers of those who are going to come after us, and that is what we can do to get that number to 100% on the cure side and 100% on the quality of life side.

Chagpar As we are moving along, particularly in pediatric oncology, we have seen some huge successes in terms of really pushing longevity and quantity of life and also quality of life. Can you talk a little bit about what are the risks? Because we have mentioned it previously on this show, that we do see a lot of pediatric patients who make it through their bout of cancer and they get to long term survivorship, but you wonder about what their risks are, what the risks are of getting another cancer? What are their concerns? I know that some of these are addressed in your survivorship clinic, but can you talk a little bit about what their concerns are, or what kinds of questions you hear from them every day?

Kupfer When you are talking about a growing and developing child sitting before you and a concerned parent who is focused on that and looking ahead to seeing that child grow up to be happy and healthy, you can imagine that that discussion is an ongoing one. Survivorship starts on day 1 of diagnosis and so that discussion starts from the very beginning and it is really, as I tell my students and residents, it is a head-to-toe issue. It starts at the top of the head in the brain and it goes all the way down to their feet and everything in-between. Especially evident in children when you are focused on how is their growth and development going, are they reaching their maximum potential height? Are there any issues with her fertility, pituitary gland, as a result of having had radiation because of a brain tumor or postoperative after surgery? There are just so many different issues. Some long term issues have greater magnitude and others are based on the particular type of therapy. There is always overhanging the diagnosis of cancer, an additional diagnosis of cancer. Just the mere first diagnosis of cancer means that your lifelong risk of getting cancer again is greater, forget about any of the therapy that you have been through. So it is really a head-to-toe issue that demands that a comprehensive view and that means that we do not forget about these patients once they are done going through their therapy, we have to maintain a very close eye on them. For patients who need that specialized survivorship care there is the availability of our comprehensive pediatric survivorship clinic, the HEROS Clinic, but actually all of us who practice in the clinic and who have continued to follow our patients, are engaged in

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survivorship care. We pay attention to our patients from head to toe whether it is getting our endocrinologists involved, to addressing the pituitary gland that was damaged by radiation or getting cardiology to examine one of our patients who has heart issues after getting Adriamycin following solid tumor chemotherapy. It is every aspect of growth and development, it is just much more magnified in a parent because we are watching these children grow up into adulthood.

Dr. Gary Kupfer is Professor of Pediatrics and Hematology, Oncology and of Pathology at the Yale School of Medicine. If you have questions or would like to add your comments, visit yalecancercenter.org where you can also get the podcast and find written transcripts of past programs. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.