

Yale CANCER CENTER *answers*

WNPR Connecticut Public Radio



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**Bringing Clinical Trials into the
Community**

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Welcome to Yale Cancer Center Answers with your hosts doctors Anees Chagpar, Susan Higgins and Steven Gore. Dr. Chagpar is Associate Professor of Surgical Oncology and Director of the Breast Center at Smilow Cancer Hospital. Dr. Higgins is Professor of Therapeutic Radiology and of Obstetrics, Gynecology and Reproductive Sciences and Dr. Gore is Director of Hematological Malignancies at Smilow and an expert on myelodysplastic syndromes. Yale Cancer Center Answers features weekly conversations about the research, diagnosis and treatment of cancer and if you would like to join in, you can e-mail your questions and comments to canceranswers@yale.edu or you can leave a voicemail message at 888-234-4YCC. This week it is a conversation about bringing clinical research into the community with Dr. Andrea Silber and Jose DeJesus. Dr. Silber is a Clinician and Associate Clinical Professor of Medicine and Medical Oncology at Yale School of Medicine and Jose is a Community Health Educator at Yale. Here is Dr. Anees Chagpar.

Chagpar Maybe we can start out by both of you introducing yourselves and telling our listeners a little bit about who you are and what you do. Andrea, we will start with you.

Silber I am a breast medical oncologist and I have actually been in New Haven since 1981. I have seen amazing things happen in terms of the cancer center, but unfortunately, I still see that cancers tend to do worse in a lot of inner-city patients. They may come in with advanced stages. They may not do as well with the same kinds of treatments and despite all the wonderful things that have happened, this is a fact that has not changed and that is one of the things that I really want to work with.

Chagpar Jose, how about you tell us a bit about yourself?

DeJesus I am brand new to the Yale University Family. I have been here since December working with Dr. Silber and Dr. Jones on a couple of different projects and again that is what our focus here today is, to try to bring that knowledge to the community and to get greater participation of racially diverse populations into clinical trials.

Chagpar Andrea, why is it that people in the inner cities, people of racially diverse ethnicities, lower socioeconomic status, why is that they do worse?

Silber That is a very complex question but there are some things that we know, first of all, there are increasing chronic conditions such as diabetes or obesity that may make certain kinds of cancer treatments more problematic. Access to care, even though there is access around New Haven in terms of transportation, a lot of inner city patients live around the Cancer Center, but they may not have access and they certainly may not have access to clinical trials, no one tells them about clinical trials, no one tells them about changes in cancer screening or things that may help allow people to do better or present at an earlier age stage and then some of the things are just intangible, why the people do worse, those are important

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clinical questions and fortunately, we have very good scientists at Yale who are looking to try to find some of the answers.

Chagpar So some of it may be biologic, but some of it in terms of access, when we look at the studies on why certain populations do worse, one of the things that always comes up as a predictor was insurance status. Now that has changed with the Affordable Care Act, people should be getting insurance, do we still find that is an issue?

Silber Unfortunately, it still is an issue. People when they are on say, Access Connecticut, they still worry. They worry about being billed, even though clinical trials are covered by the Affordable Care Act and that is one of the wonderful things about the Affordable Care Act, but people are still worried about walking into a walk-in clinic and who is going to pay for that and many people do not have primary continuity of care so they do not get some of the screening tests and they come in an emergency setting.

Chagpar Let's talk about that. Because I think one of things that is very common, we talk about it a lot on this show, is the fact that if we can find cancer early, oftentimes we can catch it when the treatments are much more effective and people do much better, so are there screenings available in the inner cities? Are people aware of screenings and the fact that they can get them often for free as part of preventative care that is covered by the Affordable Care Act?

DeJesus It is great that you just mentioned that because Yale Cancer Center and Smilow Cancer Hospital, we have just launched a new program dealing with screening and prevention, and we find that the information in these neighborhoods, and being born and raised in New Haven and in the Hill section of New Haven, the mentality is, I am not going to go to the hospital or to the doctor until I have a symptom and until there is something wrong and that mindset is one of the greatest barriers that we need to change because for my family, my generation, if you are healthy, you do not go to the doctor, and the people that go to the doctor are sick and the whole premise about screening and getting folks early is to screen atypical, no symptoms, and that message is extremely difficult to reach to a lot of folks in my community.

Chagpar So how do we get that message out? I mean, I get it, why would you go to the doctor if you are not sick and why would you have the test if you are not sick, so how do we get the message out?

DeJesus There are several different ways that we are trying to address that here at Yale, and my position is in a lot of outreach and community involvement, trying to meet with the stakeholders in the community, civic organizations, schools, churches, people that really have something to say in the community, getting that information out to those folks and then disseminating that to the public at large, that is our biggest goal that we are trying to do right now.

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Chagpar Andrea, is it just a matter of education or is it a matter of service provision, how do we improve screening?

Silber I think there needs to be a change in culture, that is the culture in the community and it is the culture at our institution making it possible for people to get screenings and get screenings in the right manner, for example, with breast screening, someone comes once and does not follow up on abnormal, that is not screening, and that is one of the interests of the National Cancer Institute, why do people from lower income backgrounds who may get a screening test not follow through with abnormal? And as we all know, it is not going to help if it is not periodic screening and with appropriate and timely follow up, so I think there are going to be programs and shifts in the University and then in the Cancer Center that are going to make a difference. For example, people who work in poorly paid jobs, they cannot take phone calls during the day, they cannot leave during the day, there are adaptations that we are going to need to make if we are going to make a difference and I know that even raising awareness of how certain low income groups live, how different cultures function, yes, maybe they will bring their kids to the office with them and I know that is probably not something I am supposed to talk about, but we have to, in certain cultures, it is helpful if you can get the entire family involved and the entire family to buy in, so those are ideas that we are trying to make a reality.

Chagpar Is it that people do not follow up on abnormal because the scheduling is such that they are being called in the middle of the day instead of on a Saturday, for example, when they can have a followup mammogram or is it that they do not follow up because of fear and the idea that well, jeez, I do not want a diagnosis that I do not want to get?

Silber You bring up a great point, no one wants to hear once you have had a test that it is abnormal and you need to come back but I think also we have other people from the community who have really volunteered as service ambassadors and say, you have got to move forward and if you have a cancer diagnosis, you need to get it treated. I am so grateful to some of my patients who all have breast cancer and have been instrumental in saying, you have got to move forward, you cannot let fear keep you down and keep you from getting the appropriate treatment, so yes, it is going to take a while but I do think we are making a difference.

Chagpar At the top of the show, we talked a little bit about clinical trials and it sounds like that is something that is really important, but Jose, can you tell our listeners why clinical trials are important, I mean for a lot of people, they think about clinical trials as being human experimentation and they do not want to be a guinea pig and here you are saying to people, not only should you go to the doctor, not only should you get a screening test and then follow up when it is abnormal, but by the way, you should really think about clinical trials. For a lot of people that is going to sound really scary.

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DeJesus Yes, you are right, a lot of people are scared and most people have the misinformation that clinical trials are for last stage treatment of cancer or the last resort when in fact that is false. There are huge gains right now happening in clinical trials at every stage of cancer progression, so that is the challenge because for many years, you thought of clinical trials as doomsday, but that is not the case anymore. At every stage there are many different types of incredible clinical trials that are happening right now all across the country, so to bring that information to the patient and not only to the patient but to the area physicians, that is what we are trying to do with this program.

Chagpar Andrea, particularly in minority populations, there is a lot of fear around clinical trials because there has been a lot of history that has not been so pleasant around minorities and clinical trials and I think that causes a lot of trepidation, so how do you allay some of that fear?

Silber I would like to also just highlight what Jose said, clinical trials are great clinical care and I think it involves a certain sort of education of saying you are going to get to see your doctor, you are going to be able to get the scans that so many people want, often you see in minority populations the fear that they are not going to get as much testing or as much care as other people or when you are on a clinical trial, that it is mandated, so that is kind of the first step but the other strategy that we use are patients who have been on clinical trials and who have really done well and just a sense of altruism that is seen in minority communities which is unbelievable and it is something that we all can leverage for the better of our whole city that people say, even if I cannot be helped, if I can help someone who is like me or if I can find out information that is going to help my daughter or my niece, I am going to go forward and that is something that is very beautiful and it is very prevalent.

Chagpar I think one of the things that is really important just to echo a few things that both you and Jose have mentioned is that clinical trials are great clinical care, it is always comparing standard of care to what we think is better.

DeJesus And sometimes the clinical trial level of care is greater than you would get if you were just getting your regular care through your regular doctor, so that level of care that is what we need to spread into the communities, we need to let folks know that the level of clinical trials is often more than what you normally get.

Chagpar Absolutely. We are going to talk a lot more about clinical trials right after we take a brief break for a medical minute. Please stay tuned to learn more information about clinical trials in the community with my guests, Dr. Andrea Silber and Jose DeJesus.

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*Medical
Minute*

There are over 13 million cancer survivors in the United States and over 100,000 here in Connecticut. Completing treatment is an exciting milestone but cancer and its treatment can be a life changing experience. Following treatment, cancer survivors can face several 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 to help keep cancer survivors focused on healthy living. The survivorship clinic at Yale Cancer Center focuses on providing guidance and direction to empower survivors to maximize their health, quality of life and longevity. This has been a medical minute brought to you as a public service by Yale Cancer Center and Smilow Cancer Hospital at Yale- New Haven. More information is available at yalecancercenter.org. You are listening to WNPR, Connecticut's Public Media Source for news and ideas.

Chagpar Welcome back to Yale Cancer Center Answers. This is Dr. Anees Chagpar and I am joined tonight by my guest, Dr. Andrea Silber and Jose DeJesus. We are talking about community access and awareness of clinical trials and right before the break, we were talking about how clinical trials are oftentimes not only a better standard of care and not only a better level of care but really afford patients better outcomes, because so often, the medications, the therapies, that you can get on a clinical trial, you cannot get off of a clinical trial and oftentimes, these are medications and therapies that we think are going to be the next generation and we think are going to be better than what we have currently, but so often there is fear, particularly in underserved communities, with regards to clinical trials. Andrea, is it not the onus of the doctor seeing the patient to talk about clinical trials? How do you engage communities in having awareness and involvement in clinical trials?

Silber One of our strategies is a program called OWN IT, which stands for Oncologists Welcome NewHaven Into Trials, and the goal is to try and reach certain segments of the community, and one is the doctors who take care of patients in the community, people who work at the clinics and other health providers at the clinic such as Fair Haven or Hill Health, and we partner with Project Access to increase awareness for the patients, community patients trust, because that is often the first place you hear about clinical trials, so Jose and I were both at Fair Haven talking about what clinical trials can do and I would like to mention though that when you say doctors tell people about clinical trials, that is something that I think on a policy level, we can do better, it takes a long time to talk to someone, particularly someone who speaks English as their second language, about a clinical trial to make sure everyone understands and is on board, and the way our medical day is set up, it really does not allow for that, it is not incentivized and that is something that I think can change. I always say coding allows you to code for someone who has a little problem in the left upper portion of their ear, but if someone needs to have a translator and you need

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to talk to the family, why is there no code for that? It would make our bosses happier as a way to justify how we spend our time and it is really important that you need physician commitment to do this correctly and ethically.

Chagpar And what about reaching patients and trying to demystify what a clinical trial is, I mean are there efforts to get out into the community and talk to people?

DeJesus Yes, we have only been running about 90 days now since I have been here at Yale, so it has been challenging but it is very rewarding to finally start connecting to the community, to the stakeholders and the shareholders here in the community and bring the message out to their constituents. A lot of times you might get the information to the upper rung of the organization or an agency, but it does not get disseminated. What is really exciting that we are seeing now is that that message is getting to the ungrounded person out in the street and that is what we are trying to do with this program. Not only have we one place where the patients can find out the information but also physicians and providers, one stop shopping that you can go to and find out what is happening, so then we can disseminate that information to the general public.

Chagpar But how does that work exactly, because if you are in the general public and you are particularly in an underserved area that does not go to the doctor, you do not have cancer because you have not gotten screened or you have not followed up on an abnormal tests, so aren't clinical trials a little bit irrelevant for them, how does that work for them?

Silber You bring up a very good point, we would love to find people at an earlier point in their illness but it is really about getting our self into different parts of the community, I have gone to church groups, to high schools and middle schools and also have community partners. It is often centered around someone that they know who has had cancer and then they say, would you be interested in coming and talking say at our women's church group and going out there and then afterwards people have interest, they say, well I have a friend who has breast cancer, I have a friend who had an abnormal mammogram, what should she do? And you might say, how many people are we reaching or that is really not about clinical trials, but it is about building a foundation and so that when someone is diagnosed, there is a level of trust and a level of interest and in my own practice, I have been able to find people of diverse backgrounds who want to participate in studies but you cannot just start out and say, we are going to double our approval, that is not really what it is about, it is about partnering to make health and particularly cancer outcomes better for our neighbors.

Chagpar And it sounds like although OWN IT is about trials, it really will start a conversation that is much more than just about trials.

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DeJesus It is all about education, I think the only way that we can begin to address a lot of these serious issues that we are facing in health disparities is education at all levels, bringing that education to the common man in the street, to the family, to the kids in school, to have a paradigm shift, to have screening and information on clinical trials and your health be something normal that you talk about every day; a lot of folks do not have that regimen for whatever reason, for whatever cultural situations that they are living in or whatever, that is not something in the forefront, staying healthy and those healthy conversations are something that we are not having and this is what we are trying to do, to bring those conversations into all aspects in the community because it will affect a whole bunch and not just clinical trials but diabetes and obesity and what have you.

Chagpar Right.

Silber Jose makes an excellent point, I have a patient who was recently on a clinical trial and when she finished her clinical trial, she said, I am healthier now than when I first came in to see you because she has had numerous interventions, it is not only about treating the cancer, it is about making sure that her diet is healthy, that she exercises, that she gets her other appropriate cancer screening, that she does not smoke cigarettes, all these things, that is a change, and it is a positive change and as a change, I think that one of the things that is so gratifying for me is the change that people feel good about and that is what our goal is, to make everyone feel good about what they are doing and that goes for some of the physicians as well. I know when I trained a while ago, there was this idea, certain people are “appropriate for clinical trials.” In other words, meaning that they are educated, that they are health seeking, that they are people who come in empowered, but that has really changed now because those people almost do not really need our help, they will find it. The people that need our help are the people who in many ways do not know how to ask or how to access and that is really what Jose and I are trying to do.

Chagpar I think that the education piece is so critical so that even though you might not have a cancer diagnosis now, if and when, God forbid, you ever do or if and when your cousin, your sister, your friend, your neighbor does, that you are an advocate for getting your health screenings, getting appropriate treatment, following up on that mammogram, getting into clinical trials, but Jose I want to ask you, it seems to me that in that education process, which as you mentioned is really not just about cancer clinical trials and in fact it might not even be just about cancer, it is about healthy lifestyles.

DeJesus I was just going to say that, it is about lifestyle education, exactly, it is about trying to have folks see that what they are doing maybe is not the best for their own health and giving them alternatives and that is easier said than done because there are so many different levels of how people learn and how people retain information, so that is the challenge that we face, it is not just, hey here is a pamphlet, read it and you are good. There are going to be some times where there has got to be demonstration where you are going to have to lead the people by their hands and you are going to have to show them. It sometimes

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will be audio and different presentations and face-to-face meeting in the churches where they feel comfortable and safe and going out there and giving that talk to the men's group or to the women's group or what have you, so those are the things, it is not that one prescription is going to cure this all, it is going to be very different interventions and at different levels of those interventions.

Chagpar And it seems to me that it is even beyond just education because you can educate somebody on what to eat but if they live in a food desert that is not changing anything. You can tell people to exercise but if there is not a safe neighborhood or a park or a playground or sidewalk, that is going to be a little bit harder, so Andrea how do you take this conversation to policy and advocacy?

Silber That is exactly where we would ultimately like to go. New Haven is a great community because there are a lot of very interested and committed people, we have a great university where there are many disciplines that are interested in problems of poverty and poor health, but it cannot only be about New Haven, it has got to be about our State, our Country and ultimately the World, and we start small, but we hope that our programs can serve as a model and New Haven is a microcosm of what you see in so many places. I see families that have been decimated by early mortality. It is really shocking when you interview a patient and find out that her siblings, only 50% of them made it past the age of 50 in the United States in a wealthy country, it is shocking and upsetting but to know that we can do better is what keeps me going and that is what keeps us all going.

Chagpar In your educational efforts, has there been a move to knock on the doors of the policy makers and say, hey, poverty is an issue and it is an issue not just about the work place and about getting jobs and about the economy, it is actually a health issue about business development and getting grocery stores that actually have fresh fruits and vegetables, is it not just a business issue, it is a health issue, has that happened in our communities?

Silber I have actually met with some community leaders including some people from the community action agency and trying to partner with other organizations that are really motivated by the same things that we are motivated by and I think it has been a nice, although somewhat preliminary, kind of discussion because for these leaders it is like the first time that people from the Cancer Center are interested in this but this is not really cancer, but poverty and health and economic development affects us all and that is the other thing. Cancer care, there are other reasons besides just it is the right thing to do, I do not mean to be preachy or anything that sounds judgmental, but it is the economic right thing to do as well because cancer care is really expensive and if we do not intervene early and intervene appropriately, everyone is going to be paying for it.

Chagpar Jose, it seems to me that the other thing that all of these programs do is develop that trust and that partnership and how do you think that affects people in terms of actually seeking care because as you say

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Andrea, it is about actually going to the doctor, actually getting the care and so often the fear is a paralyzing factor, do you find that your programs are actually getting people to go to the doctor?

DeJesus You are exactly right, and that feeling that, I know someone that works there, that I know someone from there, that each one teach one type philosophy, I think that is what works best in these certain situations because the fear sometimes is tangible, it is paralyzing to some folks and it is nice that they can say, I have seen Jose, I saw Dr. Silber at my church, at my school, at my community center, they were at a festival, this guy gave me a pamphlet at the Hill Day here in New Haven and making those connections and making those bridges I think is an important key.

Jose DeJesus is a Community Health Educator and Dr. Andrea Silber is a Clinician and Associate Clinical Professor of Medicine and Medical Oncology at Yale School of Medicine. We invite you to share your questions and comments, you can send them to canceranswers@yale.edu or you can leave a voicemail message at 888-234-4YCC and as an additional resource, archived programs are available in both audio and written form at YaleCancerCenter.org. I am Bruce Barber hoping you will join us again next Sunday evening at 6:00 for another edition of Yale Cancer Center Answers here on WNPR, Connecticut's Public Media Source for news and ideas.