Disparities in Cancer

Guest Expert:
Lyndsay Harris, MD and Tish Knobf, PhD

Yale Cancer Center Answers is a weekly broadcast on WNPR Connecticut Public Radio Sunday Evenings at 6:00 PM

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Welcome to Yale Cancer Center Answers with Dr. Francine Foss and Dr. Lynn Wilson. I am Bruce Barber. Dr. Foss is a Professor of Medical Oncology and Dermatology specializing in the treatment of lymphomas. Dr. Wilson is a Professor of Therapeutic Radiology and an expert in the use of radiation to treat lung cancers and cutaneous 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 1888-234-4YCC. This evening Francine and Lynn are pleased to welcome Dr. Lyndsay Harris and Tish Knobf. Dr. Harris is an Associate Professor of Medical Oncology, Director of the Breast Cancer Disease Unit and Co-director of the Breast Cancer Program at Yale. Dr. Knobf is American Cancer Society Professor at Yale University School of Nursing. Here is Francine Foss.

Foss Can you start off by telling us a little bit about disparities and what they are?

Harris What disparities means is a difference in how certain patients do when they are diagnosed with cancer. For example, we know that some patients with the same type of cancer have a better outcome or better survival than others. That is called a disparity, when there are differences in outcomes with the same type of cancer.

Foss In what types of cancers are disparities known to exist?

Harris The most well documented types of cancer that disparities are found in are breast cancer, colon cancer and prostate cancer. In fact, there has been at least a decade’s worth of research suggesting that people diagnosed with these types of cancer can have very different outcomes depending on race and other environmental factors.

Wilson What sort of research was done to determine these disparities? Was it looking at large groups of patients, their clinical outcomes, or looking at different types of treatments? How do we learn this?

Harris There are many studies that were done with the SEER database, which is a large national database looking at outcomes from cancer by race and these studies showed that, for example, African American patients with prostate cancer had a different prognosis than Caucasian patients with prostate cancer. Many studies have been done both in this country and the international setting suggesting that there are differences in cancer survival depending on race.

Foss Lyndsay, are there differences in the incidence of these cancers as well as survival in these different races?

Harris Yes, in fact, the differences are somewhat counter intuitive at least in North America. The incidence of certain types of cancer, breast cancer, and prostate cancer, may be lower in African Americans whereas the risk of dying from breast cancer is higher in African American women. So it is not simply a matter of incidence, there is a difference in how well these people do and the

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work that is being done now is to try and tease out what some of the underlying reasons for that are.

Foss What have you learned about that?

Harris We, and others, have studied the different possible reasons for this. They vary from environmental factors such as social environment to underlying health issues, other types of diseases which may affect the way a patient is treated. And then there are clearly genetic differences by race that are only now emerging as important reasons.

Wilson Can you talk to us a little bit about the observation that some African American women have a more aggressive type of breast cancer. What do we know about that?

Harris It turns out that not only are there differences in the rate of screening and the social environment and other diseases, but there are clear differences in the genetic makeup of tumors from women of color, particularly African American women where it has been studied the most intensively. It appears that young African American women, premenopausal African American women, are more likely to have a type of breast cancer called triple-negative breast cancer and that type of breast cancer is more aggressive, it occurs in younger women, and it tends to have a less favorable outcome in the long run.

Wilson We can have disparities among different racial groups, but we can even have some disparity within the same racial group, does that impact the treatment recommendations that you make for the patient? How specified are the treatments?

Harris In breast cancer we have become very specific about the type of breast cancer and the treatment that is required, or offered. Triple-negative breast cancer gets a certain type of treatment because there is no current hormonal or biological therapy available for this type of cancer. Chemotherapy is the most effective type for triple-negative breast cancer at the moment, but there are a number of other very interesting and exciting possibilities for this type of breast cancer that are just emerging now.

Foss Lyndsay, you stressed the importance of potential genetic changes in these tumors between African American and other groups in terms of breast cancer, and I am wondering, how do we actually detect those genetic changes?

Harris We have worked quite hard to profile these tumors from different racial groups, from black and Caucasian patients, and there are numbers of very elaborate types of testing that can be done nowadays, mostly in the research setting, where we perform microarray profiling, for example. What these tests do is give us a genomic fingerprint of the tumor and we can see that the profile is very different from triple-negative breast cancers from African American patients and Caucasian patients.

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So, these kinds of genetic analyses depend on having tumor tissue available. Is that fresh tumor tissue or could a patient who had a biopsy say at another center have their tumor screened as well?

The technologies are advanced to the point that even archived material from old paraffin blocks can be used to profile these tumors. What we have recently done at Yale is profile tumors that were 15 years old from old blocks from different racial groups and found very interesting changes.

Lyndsay, can you explain in more detail what this tumor block is, how it is processed and how we go about getting that from another center, for example, if you want to analyze that here at Yale?

The tumor block is what the pathologist will generate after the surgeon has removed the cancer. The tissue is then fixed in formalin which is a type of material that keeps the tissue from degrading and then it is put into, essentially, wax, which is paraffin, a form of wax, and the tissue is then fixed in the wax and can be stored for many decades. Those blocks are usually collected for every patient with a diagnosis of cancer and kept in the pathology departments for 10-20 years depending on the department. In order for a patient to have their tumor tested, it would require retrieving that block from the original pathology department. The utility of doing that at this time varies. There are some situations where we do tumor profiling for making clinical decisions. In the case of triple-negative patients that has not yet become a clinical test that can be used, but I think in the next few years it will be.

Lyndsay, just to let women in the audience know, this genetic profiling has not been a standard approach until recently, and in the past we had not been aware that these disparities existed between different racial groups.

That is absolutely right. The profiling has become more useful in ER positive breast cancer where there is a clinical test called Oncotype, but in triple-negative breast cancer, it is still in the research phases. This is an emerging technology that will become more and more helpful in the next few years.

Obviously, Dr. Harris, we have screening programs for certain types of cancers, could access to that screening impact disparities, or is it more just the disease itself that is causing the disparity issue?

There is no doubt that access to care is part of the reason for disparities, and in the African American population this may be seen more so in older women, but there is absolutely no question that limited access to care due to either socioeconomic factors or comorbidities can all lead to differences in the rate of screening. What various studies have shown though is that even when the screening is done as it should be, there may be a difference in follow-up for certain racial groups and that the likelihood of coming back for a second screening test may be lower, so I think there are multiple levels at which access to care can be a problem that leads to disparities.

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Foss
Lyndsay, we are talking a lot about African American women, but what about Hispanic women and Asian women, do the same kinds of problems exist in those racial groups as well?

Harris
Yes, in fact there is emerging data that Hispanic women also may have a more aggressive form of breast cancer and certainly the same issues around disparities exist for underserved populations. Dr. Knobf has done a lot of work in the area of trying to understand what some of these differences are and how they may impact on a patient’s likelihood of getting to care.

Knobf
I think one of the issues in terms of access to care is also just utilization of available screening and for some other minority populations education is important. For the African American women, there is a project called Witness Project, which is very active in Connecticut and tries to get the message out to women about the importance of mammography. We also conduct an annual ‘Hope Not Fear’ conference in October, which is a great way for women of all races to become better educated not only about screening, but also about treatment for breast cancer. For the community there is a Yale Mammography Van, which goes around the city and often to many of the Community Health Centers and we also have a breast and cervical screening program that provides free mammography for underinsured and older women and also we’ll figure out a way to cover the cost if in fact someone does have an abnormality that is found. So there is education and there are services even for women who lack appropriate insurance.

Foss:
I think that is a very important point for people nowadays given the fact that there are a lot of folks without insurance, that they do have this resource available to them.

Wilson
We are going to take a short break for a medical minute. Please stay tuned to learn more information about cancer disparities with Drs. Harris and Knobf.

Medical Minute
It is estimated that nearly two hundred thousand 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 his lifetime. Major advances in 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. da Vinci Robotic Surgical System is an option available for patients at Yale that uses three dimensional imaging to enable the 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 Broadcasting Network

Wilson
Welcome back to Yale Cancer Center Answers. This is Dr. Lynn Wilson and I am joined by my

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co-host Dr. Francine Foss. Today we are joined by Dr. Lyndsay Harris and Dr. Tish Knobf and we are discussing cancer disparities. Dr. Knobf, continuing along the lines of trying to understand more about disparities, what are some of the differences among different groups that contribute to disparities?

Knobf For groups that we know have different outcomes such as African American women with breast cancer and the Hispanic women, we know that they have a much higher incidence of what we call, lower socioeconomic status, meaning lower educational levels and lower paying jobs, and this definitely contributes to the ability to understand what is going on in cancer, access to resources, many of them have competing life demands and this really was very confirmatory of a Connecticut survivor needs assessments done last year in over 15,000 cancer survivors in the state of Connecticut and from that survey we learned that African American and Latino women had many more areas of needs in terms of resources, knowledge, gaps in access to service and it really confirms what we knew before we did our local survey, that it is much more challenging for some of these populations.

Foss Just out of curiosity, Tish, how often is language a barrier and not having materials translated into a different language for these women?

Knobf I think it is a barrier obviously for the Latino population and again, Latino women or men who have less years of education probably speak their language more often and are less fluent in English and this is an issue in terms of access to care, but it is also an issue once they get to care because when there is a language barrier between a provider and the patient it compounds the difficulty of understanding the information that is communicated back and forth.

Wilson Dr. Harris, we talked about this a little bit in the beginning of the show, but tell us a bit more about how actual treatment affects these outcomes in the different disparities for the various diseases not breast cancer, but give us some of your experiences in the other areas as well.

Harris This is one of the less well researched areas, but it does appear that there are some differences in treatment outcomes. What that means is that the patient may be less likely to complete the treatment that is recommended, less likely to undergo what would be considered national guidelines of treatment, and if they do undergo treatment, there is some evidence in different cancer types that the adherence to the treatment may be lower in certain socioeconomic and racial groups. As you can imagine, if optimal treatment is not completed, patients may not do as well in the long run.

Wilson It is obviously complicated, you have got education, access to care, resources, language barriers, different treatments, different genetics, so of all of those things what is your sense of what is the most substantial, or do you think it is really an amalgamation of many factors and too complicated to synthesize into one or two specific areas.

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Knobf  It is complicated, and difficult. In research that I have done in the past six to eight years with African American breast cancer survivors, we have learned that they are the best teachers. The experience is unique, there are some things that are similar to all races such as the fear of dying, fear of recurrence and uncertainty, but when you look at a particular culture, there are many unique factors. The women told us that providers are not very good at skin assessment, it is much more difficult to assess darker skins, for instance with radiation therapy, and one of our radiation therapists Dr. Moran has actually looked into this and confirms that there are differences in reactions among women of color versus light skinned women. Just from a cultural perspective, many women have different ways of support and coping. African American women have a very strong bond with other women often called sisterhoods and this is a major strategy of support for them. There are also things that we need to learn in terms of managing their hair loss. African American women often will prefer to go bald with really big jewelry and with a scarf versus some of the wigs that are available that might not match themselves as well. There are a lot of unique issues for minority women experiencing breast cancer that we still have a long way to go in learning and helping them cope in the best way they can.

Foss  Tish, how difficult is it for these women to convey these concerns to their healthcare providers? How often do they speak up about difficulties that they may have understanding the treatment, just the logistics of getting to the treatment and how they are feeling during the treatment?

Knobf  I think it is challenging, and whenever you look at a minority population, there is always what is cited in the literature as equality and partnership and communication and a power base, so even the average well-educated white person may sometimes feels vulnerable going to a physician because you might not be as knowledgeable, but these minority women sometimes even feel more vulnerable in terms of discussing it and if you look at the entire population, the incidence of breast cancer actually is lower among African American women so that in any given oncology practice there are probably more white women then black or Hispanic women and so we have to keep our antennas up about what their issues are and help to empower them, and that is part of the work that I have been doing the last several years in a project called Connecting Sisters, which is to educate and empower women of color to engage in their care as a partner.

Wilson  Can you tell us a little bit more in detail about that program and any other resources that are available in the state to address disparities?

Knobf  Yes, we had a project called Connecting Sisters where we identified local groups. In the greater New Haven area there is a group called Sister’s Journey, there is also a group called the Nubian Sisters and we invited all of these groups, including some groups from Bridgeport, to a meeting about once or twice a year to talk about what their issues are, how to mobilize community resources, what their needs are, how to educate women, and this was a very interactive project and we actually transitioned now all of these contacts with these groups for outreach to the ‘Hope Not Fear’ conference and we have now continued on doing research but that was really the foundation for the current study I am doing with the Lance Armstrong Foundation and that is a six-week...
educational, interactive, psychological support educational intervention focused on physical activity and healthy eating for women of color who are cancer survivors.

Foss And is that for all types of cancer, or just for breast cancer?

Knobf We started out focusing on breast cancer because that is the group we were targeting, but we accepted women with other cancers as well, as well as other women of color such as Hispanics.

Foss Tish, are the families involved in this at all, or are these programs geared primarily for the patient?

Knobf The programs have been targeted primarily to the patient but with the Lance Armstrong, they could bring a partner, which did not have to be a breast cancer survivor. They tended to bring another female partner, sister, or neighbor rather than a spouse or another male from the family, but in our Connecting Sister Project, through the year husbands or spouses usually came to the meeting.

Wilson Can you tell us a little bit more about the research that you have been doing in this area and share with us some other details?

Knobf We are excited about the Lance Armstrong Study that we did because we just analyzed preliminary data for the Survivorship Conference in June and we think that the six week interactive intervention actually improved quality of life and improved women’s healthy lifestyle behavior, so they were exercising more and eating better. Dr. Harris and I recently received funding from the Komen Foundation for a training grant to train medical nursing and or public health students in disparities research and breast cancer, and one of the issues is that we do not really have a critical mass of minority providers and minority populations would like to also have providers that are similar to them, and so what we will really hope to do is train medical and nursing students who are from a disparity population. We are looking to recruit medical, nursing, and public health students who are African American and get them interested in cancer research and in cancer care.

Foss How would somebody get involved in a program like that?

Knobf Obviously we are recruiting within the School of Medicine and School of Nursing at Yale to recruit trainees with this program.

Foss Are you working with surrounding colleges throughout the state, are you trying to pull people in from different parts of the state?

Knobf For this particular training grant, no. This grant was awarded to the School of Nursing and Medicine.

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Wilson: Are there clinical trials that are available here at Yale or elsewhere that you are aware of that can try to get to the bottom of some of these disparity issues?

Harris: Yes, in fact there are a number of different initiatives based on the work that has gone into understanding what makes up a disparity, what the cause is, and I think you mentioned earlier Dr. Wilson, that there are multiple facets, so rather than emphasizing one facet I think the approach has been to try to attack all different facets. There are screening programs, there are educational programs, but there are also clinical treatment programs that try to focus on the differences in tumor biology for example. There are new data that are very interesting suggesting that diabetes may be a risk factor for triple-negative breast cancer, diabetes and obesity, and we know that certain populations have a higher incidence of that and there are actually ongoing studies now looking at the drug metformin, which is a diabetes drug for the treatment of triple-negative breast cancer. In addition, what Dr. Knobf has mentioned to you are the exercise interventions that are a very powerful intervention for both obesity and hyperglycemia and prediabetes conditions. So those are a couple of approaches that we hope can actually target some of the underlying genetic features of the disease in younger women.

Foss: At this point in time, Lyndsay, are you treating patients differently based on any of these ethnic or genetic differences? Are these leading yet to some change in care for the cancer?

Lyndsay: What we are finding is that if we parse it out, access to care and the education around care, are part of what one needs to increase awareness about, so I personally and people that I work with take extra effort to try to meet the needs and understand the needs of individuals from different racial groups, but then subsequently, the actual treatment itself has not yet changed to the point where we can focus in on the treatment for a particular racial group. There are some researchers in the field that believe it may not be so much race, but socioeconomic factors that lead to many of these differences, even the genetic ones, if you imagine, the risk factors obesity and diabetes leading to triple-negative breast cancer is not necessarily unique to a racial group, but may be more of a socioeconomic issue, so I think we were trying to understand them and therapy will be designed following that.

Dr. Lyndsay Harris is an Associate Professor of Medical Oncology, Director of the Breast Cancer Disease Unit and Co-Director of the Breast Cancer Program at Yale. Dr. Tish Knobf is American Cancer Society Professor at Yale University School of Nursing. If you have questions for the doctors or would like to share your comments, visit yalecancercenter.org, where you can also subscribe to our podcast and find written transcripts of past programs. I am Bruce Barber and you are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.