

Yale CANCER CENTER *answers*

WNPR Connecticut Public Radio



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Colorectal Cancer Disparities

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Welcome to Yale Cancer Center Answers with your hosts doctors Francine Foss, Anees Chagpar and Steven Gore. Dr. Foss is a Professor of Medicine in the Section of Medical Oncology at Yale Cancer Center. Dr. Chagpar is Associate Professor of Surgical Oncology and Director of the Breast Center at Smilow Cancer Hospital and Dr. Gore is Director of Hematological Malignancies at Smilow. Yale Cancer Center Answers features weekly conversations about the research, diagnosis and treatment of cancer and if you would like to join the conversation, you can submit questions and comments to canceranswers@yale.edu or you can leave a voicemail message at 888-234-4YCC. This week you will hear a conversation about colorectal cancer with Dr. Xavier Llor. Dr. Llor is Medical Director of the Colorectal Cancer Prevention Program and Co-director of the Genetics and Prevention Program. Here is Dr. Steven Gore.

Gore Could you tell us a little bit about what you do here at Yale and about colorectal cancer.

Llor Sure, I am Co-director of the Cancer Genetics and Prevention Program at Smilow Cancer Hospital and I am also Medical Director of the Colorectal Cancer Prevention Program here. In this role, I am working on increasing colon cancer screening rates and also integrating the different services at Smilow Cancer Hospital and Yale-New Haven Hospital for families who have an increased risk of colorectal cancer.

Gore Who should we screen for colorectal cancer?

Llor It does depend on your family history. There is no recipe that fits everyone. In general, what we call average risk individuals are individuals who do not have any family members who have had colorectal cancer. In this case, the majority of people are age 50, but we have good evidence that in African Americans we need to start colorectal cancer screening before that age, probably by age 45 as some societies have already recommended because they do develop colorectal cancer at a much earlier age.

Gore What is involved in screening, is it a colonoscopy or a stool fecal blood sample?

Llor We have we call the noninvasive and the invasive modalities. The invasive modalities basically are based on colonoscopy, using a flexible tube to inspect the entire colon and that is the most widely used screening test in the US. The advantages are that it allows us to visualize the entire colon and also to intervene, so when we see polyps, which are usually the origin of colon cancers, we can remove them on the spot decreasing the risk of colon cancer development. The other options are the non-invasive or the stool based options, which are basically looking for the presence of occult blood in the stool as most tumors, particularly as they grow, do shed some blood that often we do not see with the naked eye, but it can be detected through those tests. So those tests are usually quite good actually at detecting advanced cancers, it is not as good at early cancers and polyps as they do not bleed as much.

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- Gore I remember a few years ago, people were talking about the use of some kind of CT scan colonoscopy. Am, I making that up?
- Llor No, you are not, it is CT colonography and basically that is based on doing a CT scan with special software techniques that allows us for detection of polyps. The challenges with the CT colonography, number one, is that there are a significant number of polyps that do not grow towards the lumen, they grow towards the inside of the mucosa, which is something that is harder to see, but still most of the time we can see them on colonoscopy but they are very difficult to see on CT colonography. So, those cases are harder to see and also there is an issue about the size of polyps that can be detected, in general, small polyps may not be detected. What that means is unclear because some polyps we do know actually do not progress into cancer, but still there are some questions that need to be answered before CT colonography is generalized. At this point, there are developments in terms of developing new software tools for this and it is probably something we will hear more about, but for now it is not preferred method of colon cancer screening.
- Gore It sounds like when you are in your 50's, you should go ahead and get your colonoscopy?
- Llor That is definitely always the message and that is because we have enough studies that show us over and over that colon cancer screening does decrease incidence and mortality from colon cancer, and screening for colon cancer has been one of the big successes over the last few years in the US, as we have seen the incidence going down in a very steady way and for the most part this is linked to this adoption of screening techniques and the generalization of the screening methods.
- Gore I think some of our audience may be concerned about how frequently they are going to need to have this test, which even if it is not a terrible test, it is a nuisance in terms of the preparation a couple days before. So, in your average risk middle aged person often do they need to have this screening colonoscopy?
- Llor In general, if the individual has a colonoscopy and does not have a single polyp, the preparation was good, we feel confident that we have seen everything and the person does not have any family members with colon cancer, we go ahead and say that we can wait for 10 years because we do have quite a high-degree of confidence that for the most part, the majority of colon cancers develop very slow and an individual who have never developed a polyp at age 50, the percentage that they will end up developing polyps in the future is also lower. When we have some family members who have had colon cancer and we have had polyps removed from the colon, the next colonoscopy will be tailored according to these different factors.
- Gore You said that one of your jobs here is to increase the prevalence of colon cancer screening, what kinds of action are you or your team taking to increase the uptake of colonoscopy here in Connecticut?

6:45 into mp3 file <http://yalecancercenter.org/podcasts/2014%200831%20YCC%20Answers%20-%20Dr%20Llor.mp3>

Llor What we see here in Connecticut, and in most places, is that there is a huge disparity in terms of the intake of colon cancer screening, as with most screening methods, according to different racial groups. We know that African Americans do get less screening and Hispanics, even less. Hispanics are the group that get the least screens for colon cancer. So we really want to focus on increasing the screening in these particular populations that are screened less than the_Caucasian population and in order to that we started several initiatives, one of them is a collaboration with the Fair Haven Community Health Center that basically streamlines the process of getting their patients to come and get their colonoscopies done here, some of them are under insured or not insured at all and we facilitate the process, so actually we are providing the service and hopefully increasing screening rates and decreasing colon cancer in the most vulnerable populations, and we really want to expand on that.

Gore Do you think that the financial piece, lack of insurance or under insurance is the primary barrier to screening? I am sure there must be an education piece, is there is any mistrust about coming to a place like Yale?

Llor I think there is a little bit of everything. There are well done studies that consistently show the number one cause of this disparity is truly an insurance related issue. So, that is extremely important and it is nice to hear that we have made so much progress enrolling individuals to the new health exchanges, but also there are cultural issues that you were mentioning that we really need to work on. For instance, what we are doing with the Fair Haven Clinic, which is heavily attended by Hispanic individuals, is we have streamlined the process where we are providing all the instructions and the entire process in Spanish, so they can actually overcome this barrier, if it is a language barrier. It will take not only getting more individuals insured, but also putting all the proper tools together to overcome all these limitations, but we really need to work in different fronts.

Gore How are these programs paid for?

Llor Actually the Fair Haven Yale initiative is being paid for by a grant from the American Cancer Society. We obtained this grant a couple of months ago and it is one of three grants in the entire country that is directed at increasing the collaboration of large academic institutions with community clinics so we can streamline the process and facilitate the screening of those individuals. The ACS is very interested in seeing us succeed as they see this as a pilot program for other institutions around the country to increase screening rates, so we are really hopeful we will get good numbers here and we will get a lot of individuals screened and therefore, they will see this as a model to translate it to other areas in the US and show that there are ways to do it.

10:22 into mp3 file <http://yalecancercenter.org/podcasts/2014%200831%20YCC%20Answers%20-%20Dr%20Llor.mp3>

- Gore I assume you will have to show them some deliverables that you have actually done the work and delivered the goods.
- Llor Absolutely, we need to show them that we are capable of increasing the screening rates of eligible individuals that usually attend that clinic, that we did so within a reasonable amount of time, because time is of the essence and being a screening test, if we are presented with options that are so far down the line, we probably forget and we get less motivated. So, we are working on decreasing the waiting time for individuals to get their colonoscopies and engaging them into actually coming and getting their procedures done, and also very important, working very hard and making sure people prepare well. We have a big problem, which is a lot of individuals, unfortunately are unable to complete their preparations and we do not see well and we may be missing small cancers and, therefore, it is very important that we work hard on educating so we are all better prepared and when gastroenterologist do the procedures, they are confident that they have seen the entire colon. So, those are different aspects that we need to work on to make colon cancer screening successful.
- Gore And are you hands on and go out yourself into the community to talk.
- Llor Correct, the first that we have done is a series of talks to the primary providers and we are going to spread that out and also we are helping to implement the system within the clinic itself, so it does not become another burden to the primary care provider. They are already burdened with a lot of information and most of the time they have to cover the acute sickness of what individuals come in for. Therefore, adding an extra step, which is explaining about the importance of colon cancer screening and other screening modalities is important, so we need to make it easy for them, so patients can get the message while we are still able to provide all these services and again most of these clinics are very stranded by patient care. They need to deliver a lot of care to a lot of individuals, and we have to make sure that when they engage in that it does not become yet an extra burden.
- Gore Some of these are under-served communities, the usual operating mode for patients is to come in only when you are sick and the whole idea of preventive care is probably not as common as we wish it would be, I suppose.
- Llor They have to make a big effort in tagging the preventive component when patients do present with any acuteness, because as you mentioned level of awareness about preventive measures is just not as common there. Therefore, they have to be very smart about developing this skill and making sure that when they have their captive audience, when the patient shows up there for whatever reason, they are all over the place, making sure that we do take care of the patient and that includes preventive measures.
- Gore That is great, we are going to take a short break for a medical minute and certainly we want to come back to your work in both screening and genetics.

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Medical

Minute Smoking can be a very strong habit that involves the potent drug nicotine and there are many obstacles to face when quitting smoking. But smoking cessation is a very important lifestyle change especially for patients undergoing cancer treatment. Quitting smoking has been shown to positively impact responses to treatment and it decrease the likelihood that patients will develop second malignancies. Smoking cessation programs are currently being offered at federally designated comprehensive cancer centers such as Yale Cancer Center and at Smilow Cancer Hospital at Yale-New Haven. The Smoking Cessation Service at Smilow operates on the principles of the US Public Health Service Clinical Practice Guidelines. All treatment components are evidence based and therefore all patients are treated with FDA approved first-line medications and smoking cessation counseling. This has been a medical minute brought 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 the WNPR, Connecticut's Public Media Source for news and ideas.

- Gore Welcome back to Yale Cancer Center Answers. This is Dr. Steven Gore. We are talking tonight about colorectal cancer, in particular disparities and colorectal screening, and also the genetics of colon cancer. Dr. Llor, before the break we were talking about how you are working to increase uptake of screening in underserved communities, which is really wonderful work. I know you also are interested in cancer genetics, can you tell us about that?
- Llor Sure, colon cancer, along with breast cancer, is among the group of common cancers where a genetic component has been implicated in cancer development. We know that about 15% of the individuals who develop colon cancer, have another first-degree relative who also had a colon cancer, and those individuals in those families have two to three times increased risk of colon cancer. On the other hand, we know that there are some particular genes that when they are mutated, they predispose for very high risk of colon cancer. These are what we call syndromic cases and those are inherited and they are inherited one generation after another and in those cases, the risk of developing colon cancer is extremely high, much, much higher than the average risk population and we do need take special care and attention to those families and individuals.
- Gore How would I know if I am in a colon cancer family? Is it just enough that I had an aunt that had colon cancer? Is there a certain frequency that should ring a bell for me? What should worry people?
- Llor In general, having several, not only one but several family members with colon cancer, and other types of cancer, because many of the syndromes we are talking about in individuals do develop different types of cancers, not only colon cancer. Having that, and having just a few or just one first-degree relative who developed that cancer at a significantly young age, in general, would occur above age 50, but we see cases much younger. When we see something like this, we should be aware and certainly we should seek genetic evaluation to see if those are risks factors that really put us in a category that would make it suspicious for one these syndromes.

17:50 into mp3 file <http://yalecancercenter.org/podcasts/2014%200831%20YCC%20Answers%20-%20Dr%20Llor.mp3>

Gore I imagine a lot of people see their internist or primary care physician, or nurse practitioner and if they are doing a thorough job, they usually will take a family history and so let us say I bring up these various cancers in my family, do you find that most primary care practitioners are able to make a transition to a genetics referral?

Llor That is also a big challenge and that is one of the aspects we are working very hard on and as we were mentioning before, primary care providers are suspended with so much to take care of and while the family history forever and ever has been a very important aspect of our history taking when we see a patient, it does take a lot of time and we know that we are not the best at taking good family histories, again most of the time due to time constraints. And we are working on developing tools that facilitate that process and one of the tools that we are implementing is a questionnaire that the patients will fill out by themselves and that will be turned into the clerks and the clerks will pass it on to our services, so we can spot who would benefit from a genetic consultation and this way we don't put much more burden on the primary care physician yet individuals can have their risk assessment and be called on when that is appropriate. We are also working on implementing online tools, so that individuals, from home, can fill out this information that can be passed along and that could facilitate screenings. So there are different ways of doing it and we are working on those because we do recognize that this is challenging and often individuals do not remember if we do not prompt them to start thinking about who may have had died or who may have had cancer in their family. So this tool should also help individuals to dig in a little bit into their family histories and see if there is anything that can be suspicious for a syndromic case.

Gore If I were to be referred to a cancer genetic specialist, what would happen at such a consultation?

Llor The first thing is gathering this family history, particularly all this information about family members and potential cancers or other conditions, skin conditions, other things that make you think that they have a particular syndrome. You would also look at if they already had cancer and the type of cancer they had, because some of these syndromic cases are associated more commonly with some types of features because not all cancers are alike. You gather all this information and you come up with a risk assessment and that basically gives you a rough estimate on the risk of that individual and family to have a syndromic case. With that, if we believe that the family has significant risk for having that syndrome, then there are some genetic tests where we can look for mutations in the genes that can be causing these cancers, so we can go through the full process or on the other hand, we can reassure them that actually it does not look like this is a syndromic case and have the patients reassured and not undergo any genetic testing but the risk assessment is key and it is to be done by individuals who are familiar with that and proceed accordingly.

Gore What happens if I find out that I have a mutation in one of these genes associated with a familial cancer syndrome, am I now going to just be scared to death?

22:06 into mp3 file <http://yalecancercenter.org/podcasts/2014%200831%20YCC%20Answers%20-%20Dr%20Llor.mp3>

Llor I think years back that was the thing, I am going to learn about it that I am going to develop all these cancers and there is nothing we can do about it? All I am going to do is be scared all my life. I think that the difference is knowing that there are some preventive measures that can be undertaken and discussed with the patient that have actually been shown to prevent cancers and save lives and it has been a few years since we started learning all about these different genes that cause these syndromes and starting these families on the kind of interventions that we can do to save lives, so certainly, we can be very proactive because being proactive does prevent cancer and save lives, therefore, it is a matter of doing the right thing because it will spare you from further problems. Not only psychological stress, but actually you can get a little bit of peace of mind knowing that you have that and there are things that we can do that can minimize the risk of developing cancer.

Gore What kinds of things does that involve?

Llor For instance, in one of the common colon cancer syndromes, which is Lynch Syndrome, the risk of endometrial cancer is pretty high. It is up to 40%. It varies depending on the gene that is mutated. In those cases, very often we discuss with individuals who have already passed the child bearing age the option of hysterectomy because there are studies that have shown that it does prevent cancers and does save lives. So that is an option, because most of the time those cancers do develop at a later age and therefore for the most part they may keep their endometrium until child bearing age is passed and then undergo hysterectomy. Undergoing more frequent colonoscopies is also very effective and there are also some medications, for instance in syndromes that are called polyposis syndromes where individuals not only develop colon cancer but develop a lot of polyps and some of them develop into cancer, there are some medications that actually can decrease the polyp burden and they are being used when part of the colon is taken out but the rest is still left in place and of course we will hear more about more medications preventing colon cancer. And again, one of the old friends is aspirin, and we know that it does prevent colon cancer and when we put all the benefits and risks together we should evaluate in many cases if it is worth placing a patient on aspirin for prevention purposes, so even some simple, not very well known old friends like aspirin may play a role here too.

Gore And are they using full dose aspirin or baby aspirins?

Llor It does look like baby aspirin probably is doing the same work as the full dose aspirin.

Gore So, that is good for coronary arteries and it is good for the colon.

Llor Right.

Gore That is great, now are you always able to detect an abnormal gene in these particular families?

25:32 into mp3 file <http://yalecancercenter.org/podcasts/2014%200831%20YCC%20Answers%20-%20Dr%20Llor.mp3>

Llor We have made a lot of progress and many different genes have been identified over the last 15 years or so, and certainly the progress has been dramatic but we believe that there are still some cases where we just do not find a mutation and they look like they are certainly syndromic because you have seen different family members affected in different generations. So, it still looks like there are some significant numbers of cases where we do not have the mutations detected and that is an active area of research in the field, trying to figure out more of the genes that can be implicated in that colon cancer development.

Gore Are you studying these patient's genomes?

Llor Certainly, so with the new generation technologies for genetic testing there has been an explosion of what we call a high throughput whole genome sequencing, or exome sequencing, which is basically allowing us to screen the entire genes and genomes in a very fast and easy way in comparison to what we used to do just 10 years ago. That has allowed us to really move forward with those cases and studying these families where we can still see mutations. So, I think we will hear more and the pace of discovery is still accelerating just because these tools have dramatically increased our capacity and our power to make more new discoveries.

Gore A few years ago, people were concerned about these genetic discoveries and subjecting themselves to a genetic study because of the concern that if they were found to have a syndrome or any kind of abnormal genes, that perhaps their insurance would be adversely affected. Do you have any sense for how that is since the Affordable Care Act? Has this impacted genomes?

Llor Before the Affordable Care Act, there was a Federal Law called GINA that was implemented several years ago, and many states actually have their own laws that protect against discrimination because of being a carrier or having a syndrome. We have seen no cases in the courts and I believe that you have not seen any of those yet and probably we will not see them because GINA has already been in effect for a while and that it is very specific at prohibiting discrimination because of that. That really gives us peace of mind and also lets us be more open with other health care providers sharing the information because it will result in better health care for the patients who are affected.

Gore That is reassuring for patients I am sure who have been concerned. I know that it is something that comes up in my practice. People are very concerned about the implications for insurance. Thank you for that. I would like to go back to a little bit of the disparities work and the various undeserved communities. Do you find that the characteristics of the cancer are pretty much the same?

Llor There are significant differences that we are trying to explain and certainly one focus that we have is African-Americans because of their much higher risk, or much higher incidence of colon cancer and also much higher death rate from colon cancer, and looking specifically at the African-American population there are certain features that are quite different. One of them is they

29:29 into mp3 file <http://yalecancercenter.org/podcasts/2014%200831%20YCC%20Answers%20-%20Dr%20Llor.mp3>

develop a much higher number of right-sided or proximal tumors in the colon and those are often more difficult to see in colonoscopy and more difficult to clean when the patients are taking their preparations and they also have features that often invade inside the mucosa and are harder to see and that has a lot of implications for the African American community and they deserve further study.

Dr. Xavier Llor is Medical Director of the Colorectal Cancer Prevention Program and Co-Director of the Smilow Cancer Genetics and Prevention Program. We invite you to share your questions and comments, you can send them to canceranswers@yale.edu or you can leave a voice mail 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 and hoping you will join us again next Sunday evening at 6:00 for another addition of Yale Cancer Center Answers here on WNPR Connecticut's Public Media Source for news and ideas.