

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, Dr. Chagpar welcomes Liz Margolies. Liz is Executive Director of the National LGBT Cancer Network. Here is Anees Chagpar.

Chagpar Tell me a little bit about the LGBT population and cancer. How much does cancer affect LGBT people and what are the specific issues affecting them? How much do we know, and how much do we still need to learn?

Margolies I am going to break my answer up into a bunch of key categories along the cancer continuum. As a start, LGBT people as a group, meaning not any of us necessarily as individuals, have dramatically increased cancer risks. I am a lesbian and lesbians, for example, have what is known as the densest cluster of risk factors for breast cancer such as increased tobacco use, alcohol use, as a group higher body mass index, more likely to eat a high fat diet, and less likely to have a biological child before age 30, which would offer some protection. The other kinds of risks that we see in the other subpopulations are, for a gay man, or men who have sex with men, and might not identify as gay per se, we see much higher rates of HPV, especially anal HPV, and of course higher rates of HIV. What we are now seeing in the aging HIV population is that the medication is keeping people alive much longer, which is great, but we are seeing more people die of cancer than of HIV. They are getting new kinds of cancer including anal cancer, lung cancer and lymphomas and they are getting them younger than we see in the general population and treatments are more complicated because of their HIV meds.

Chagpar It sounds like this is really an issue that affects a lot of LGBT people. Do you find that LGBT people are getting the services that they need, prevention and screenings that they need along with the general population, or are there still barriers for the LGBT population?

Margolies It is a great question, because if we are talking about a group that has dramatically higher risks, we would love to see high rates of cancer screening, but unfortunately the opposite is true. For a number of reasons which I will list in a minute, we see dramatically lower cancer screening rates in this population. Lower rates for mammograms, colonoscopies, cervical cancers, etc. and there are a bunch of barriers to care which come into play here, much lower health insurance rates, with transgender people having the lowest health

insurance rates of all. Along with previous negative experiences, or fear of discrimination, this keeps many people away from the health care system and unfortunately many health care providers, even well intentioned ones, do not have any training for dealing in a welcoming way to this population.

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Chagpar I think that those are all great points and I want to unpack each one of them. First tell us a little bit more about the transgender population and the specific risks that they have, and the specific barriers that they have. How do people in the health care system approach transgender people particularly with those risks?

Margolies Let me go back a second, LGBT stands for Lesbian, Gay, Bisexual, and Transgender and it is an umbrella term and there are two very distinct categories in there and this is often confusing for many people. Lesbian, gay and bisexual are sexual orientations, they are about who you are drawn to sexually, romantically, etc. But transgender refers to one's gender identity and for most of us the internal sense of being male or female matches the sex we were assigned at birth. So I feel inside like a female and I was assigned female at birth. For transgender people, their internal gender identity does not match and it is a huge group of people, some of whom feel like, Oh my God, I was absolutely born in the wrong body and I will do everything possible, surgery, hormones, change my documents if I can, to live my life as the other sex, and some people are more comfortable just moving along half-way down the field towards the other side. F to M transgender people, female-to-male, may have what it is called top surgery, they might have their breasts removed and that would, for example, perhaps lower their risk for breast cancer. On the other hand, there is so little research about this population and many F to M transgender people are using testosterone as part of their transition and nobody is doing any research on this. The research on exogenous hormone use and breast cancer is a little frightening, but none of these studies have looked at transgender people. Let me just go back to the whole transgender population, it has been terrible with the health care system, literally 19%, that is nearly 1 in 5 transgender people are actually turned away by a health care provider by saying, I do not understand you body, I cannot help you, I will not treat you.

Chagpar Really.

Margolies Yes, we have worked with a transgender man, meaning he was assigned female at birth, had breast cancer, and when he was diagnosed, they

did not give him his results and they instead referred him to a psychiatrist. He had breast cancer, not a psychopathology that needed to be addressed. He was living comfortably as a male.

Chagpar That is a huge issue and I think it goes into the second issue which you talked about which was that the health care system has been at times quite frankly unwelcoming to many people who may be LGBT. Can you talk a little bit about how pervasive that is and what forward looking institutions are doing to try to breakdown those barriers, because it seems to me absolutely unconscionable that nearly 20% of transgender people are turned away at the door. I cannot wrap my head around it.

Margolies Let me start by saying that many LGBT people have terrible experiences in the health care system, but some of those experiences were at the hands of well intentioned providers. So part of what we

7:46 into mp3 file <http://yalecancercenter.org/podcasts/2013%200602%20YCC%20Answers%20-%20%20Liz%20Margolies.mp3> really need to see is cultural competence training, and I do not mean a one time workshop, I mean an ongoing understanding of this culture so that providers at every level know how to extend the welcome that many do feel in their heart. Here is a simple change, although I know that it is nearly impossible to actually accomplish changing forms, but when a form says, single, married, widowed, divorced, the 20 year gay couple has no idea whether they are supposed to answer it legally and write single or answer it as partner. In Connecticut you have same sex marriage, but still many people are involved with someone who is a legal stranger to them. LGBT people might raise kids together, but only one is a legal parent, for example. So many of our relationships take place outside of the legal system, but if the form allowed for living with partner, if under sex you did not just have the options male and female, the message comes across so instantly and powerfully to this population who enters the health care system with a lot of trepidation and a lot of weariness, it says 'gay spoken here', we are not the first one they have ever met. Now many of these things, whether there are rainbow stickers some place or a more inclusive and welcoming form, are the early experience people have as they enter the health care system. Is there literature sitting out that reaches this population? Is the art on the walls all heterosexual, or does it seem to address us too? And my organization, for example, was asked by the New York City Health and Hospitals Corporation, which is the largest municipal hospital system in the country, to develop cultural competency training for all 38,000 employees and the beauty of this is that it is mandatory for the security guards, for the triage nurse, and for the person who is going to take the insurance information, because so much happens before anybody ever gets

to speak with a culturally competent well-trained, good hearted doctor, nurse, or social worker.

Chagpar Tell us a little bit more about the LGBT Cancer Network and what you do and what resources you have and who accesses them and how people get connected with you.

Margolies Let me go back to the cancer continuum which I started to describe before. We said increased risks, lower screening rates, and while I know that 2 plus 2 is 4 everywhere in the world and it must be here also, I cannot actually tell you for sure that that adds up to a greater incidence of cancer because no cancer registries are collecting information about gender identity or sexual orientation and you know how important that kind of data is, and we're buried in it, were invisible once more. Using breast cancer as an example, we know white women are more likely to be diagnosed with breast cancer and black women are more likely to die from it. What do we know about the LGBT cancer experience? When I can't show those kinds of numbers, the increased incidences or prevalence, it is very hard for us to get funding, so we operate on a shoestring and what we do with our money so far has been focused on educating the LGBT community about their increased cancer risks and the importance of screening and early detection and we have created a national directory of LGBT friendly, low cost or free cancer screening facilities across the country and as we say, there is one within driving distance of you. We train health care providers to offer more culturally competent care to their LGBT patients, otherwise I would not be able to sleep at night encouraging people to go to into the health care system unless I was also working to make it better, and we advocate for LGBT inclusion in national cancer organizations

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research and the media. We are now also seeking funding to develop some LGBT cancer survivor support groups because there are so few across the country and survivors tell us that they are desperate to speak to other people who understand.

Chagpar Give us a sense, Liz, of the numbers, the magnitude of people in the LGBT community who have been diagnosed with cancer. I realize that those numbers may be difficult to get given the fact that there is so little data and it is not captured, but what is your sense?

Margolies My sense is that we are carrying a disproportionate burden of the disease, and again, I am willing to say 2+2 is 4, if there are no scientists near me, but if there are they will not let me, but we say there are 12 million cancer survivors, I mean at least million of them have to be LGBT. Right, I mean, even if we are under a10th of the population, we are talking about a million people, many of whom are hidden, many of whom are afraid to tell their health care team for fear of substandard care.

Chagpar This is such a fascinating and really timely topic, and we are going to pick this conversation up right after we take a short break for a medical minute. Please stay tuned to learn more information about the LGBT population and cancer with our guest, Liz Margolies.

Medical

Minute The American Cancer Society estimates that the lifetime risk of developing colorectal cancer is about one in twenty and that the risk is slightly lower in women than in men and when detected early colorectal cancer is easily treated and highly curable. Men and women over the age of 50 should have regular colonoscopies to screen for the disease. Each day more patients are surviving colorectal cancer due to increased access to advanced therapies and specialized care which is giving colorectal cancer survivors more help than they have ever had before. Clinical trials are currently underway at federally designated comprehensive cancer centers like the one at Yale to test innovative new treatments for colorectal cancer. New options include a Chinese herbal medicine being used in combination with chemotherapy to reduce side effects of treatment and help cancer drugs work more effectively. 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.

Chagpar Welcome back to Yale Cancer Center Answers. This is Dr. Anees Chagpar and I am joined today by my guest, Liz Margolies. Liz is Executive Director of the LGBT Cancer Network and we are discussing issues with regards to the LGBT population and cancer. Liz, before the break we were talking quite a bit about screening and barriers and incidence of cancer and one of the things that I want to pick back up on that you have mentioned before was that with all of the advances in treatment that a lot of people are living much longer with cancer, and we have had other discussions on the show about survivorship, can you talk a little bit about the LGBT experience for cancer survivors.

15:29 into mp3 file <http://yalecancercenter.org/podcasts/2013%200602%20YCC%20Answers%20-%20Liz%20Margolies.mp3> Margolies It was fascinating for me to recently learn so much more about this, by not just doing the kind of research and

outreach that we do, but by putting together a survey that we put online, and we use social media a lot and we were able to get 311 LGBT cancer survivors across the country to answer a short survey, and the survey was focused on the moment of diagnosis, but what I want to talk about today is how 80% of those chose to answer a supplementary question at the end which was, if you were to give a class on LGBT health what would you want to let the class know about the experiences of being lesbian, gay, bisexual, and transgender and having cancer? And as I said, 80% of people took the time to write something and the responses astounded me, but even more so they deeply saddened me. I had no idea how hard it was, and you'd think of all people I should have been in a position to know, and ultimately, I would say that the cancer experience for this population is the same, only scarier, that in addition to the first question that everybody asks once they have been diagnosed, am I going to live, will I be okay, every LGBT person adds, will I be safe being who I am? Will my family of choice and my loved ones be accepted? Will we get the answers to questions we have about our sexuality, cancer's impact on our relationship and our families and our fertility? And in way too many cases the answer is no, most health care providers, cancer health care providers do not ask people as a start about their sexual orientation and gender identity, remember they are two separate categories and so many people we found who were perfectly safe being out in other parts of their lives did not come out to their cancer provider, or some said they'd come out to some providers and then not others. In fact coming out is not a one time event, every time your blood is drawn you have to decide whether it is safe to come out to that person. The x-ray technician, whoever it is, and for some people who did not have a choice about what hospital to go to because there were not many cancer centers within driving distance of them or their insurance was not accepted or they did not have insurance, some of these people got care in religious institutions and they very much feared that as one patient put it, I was afraid that the surgeon would "accidentally" forget to remove all of my lesions and the fear of substandard care is not crazy. Many people who did come out experience substandard care and those again with more privilege and options because of where they lived and their insurance or their ability to pay move doctors, change doctors, that is what I mean.

Chagpar That is as you say deeply saddening and shocking, just devastating, how do you ameliorate that? How can health care providers make it clear that this is a welcoming environment and a safe environment and one in which your care will be spectacular, no matter what your gender identity or sexual orientation or any other distinguishing feature that you want to talk about is?

Margolies I think we need a new normal. A new universal way of speaking to patients and this would not only be good for LGBT patients, but good for everybody. The simplest example of this is that many people now, when

asking for a sexual history, say, do you have sex with men, women or both? And everyone is so afraid that the straight person is going to say what! What do you mean, of course I have sex with men. Are you telling me I look like a lesbian? But if it is a universal question then you can answer by saying, I do not know what a lesbian looks like, I just ask everybody and it says, you are not the first one I have ever met and you are welcome here and this goes such a long way. Also, say whose part of your support team? Reach out and try to support

20:37 into mp3 file <http://yalecancercenter.org/podcasts/2013%200602%20YCC%20Answers%20-%20%20Liz%20Margolies.mp3> every person on that team, even those who are, as I said before, legal strangers. Let us not assume any longer that people's biological families are there for them. Many LGBT people have been rejected by their families of origin because of their sexual orientation or gender identity and these rifts are not healed with a cancer diagnosis, as I would have thought, I have to say, instead what people wrote was that they said I am so grateful that my partner was accepted because when I told my family they said they hoped I would die in surgery. So we need to make a simple new universal. I mean remembering the early years of the AIDS crisis, if you were getting your blood drawn and the phlebotomist put on gloves you would get huffy, like what do you think I have HIV? And now we do not think anything about it. It is a universal precaution. We need a new universal welcome and I think while there is a dearth of real data about this population there are a few small studies, but we need more, we need more money. This administration, the Obama Administration has been spectacular, especially in the last two years in making great changes, standing behind this community, understanding the health disparities that we face and understanding that what we need is culturally sensitive training of all health care providers. So just a good heart is not enough, you have to know what matters in this community. If you know you are treating somebody, a man who has sex with men, you might want to offer him an anal pap. if he does not come out, if you do not encourage him to come out, he will not necessarily come out. But the research does say over and over again, when invited people lead to say who they are, our good cancer care means treating the whole person and the people that we love. It is not just a matter of blood work and scans and brilliant surgery and chemotherapy.

Chagpar So true. I want to come back to some of the issues that you were mentioning in terms of current times because I think that there has been a lot in the media currently about trying to unpack many of the historical disparities that society has had, that have been discriminatory quite frankly to LGBT people and I would like you to talk a little bit about that. Particularly when you mentioned the Obama Administration, one of the things that I have noticed is that particularly LGBT population health was identified as a key goal for the Healthy People 2020 Initiative and there are others I am sure.

Margolies I would like to talk about one example to stand for all of them, and that is hospital visitation which also says more about the theme of legal strangers. More and more our lives are not set up with legalized relationships and the changes in the hospitals, as to the visitation ruling, came about because a lesbian couple had gone to Florida with their four children and one of the two women had a stroke and when she went to the hospital, obviously her partner and the four kids came and they happened to have all the legal documentation, power of the Attorney, health care proxy etc, and they were told this is Florida and we do not care about your paperwork and this woman died without being able to say goodbye to her partner of 20 something years or her children or having her children say goodbye to her, and many, many organizations banded together when we learned about this and my organization played a small part too and ultimately President Obama issued a memorandum saying that every patient can decide who they want to have visit them. It does not matter if it is your best friend, you do not have to have a legal tie.

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Chagpar That is incredible. We are very fortunate here in Connecticut to be a fairly progressive state and one of the first to have legalized same sex marriage.

Margolies True.

Chagpar But in other states, where that is not the case, are LGBT people still facing issues in terms of their health care?

Margolies Oh my God! Yes. I mean there are multiple studies that show that there is absolutely a clear relationship between discrimination and poorer health. In states that do not have protective policies for LGBT people, let's put marriage aside, I am talking about can you be fired, can you be denied service in a restaurant, can you be kicked out of your hotel for being LGBT, in 39 states you can be denied simply for being transgender, and in 29 states simply by being lesbian, gay or bisexual and in states without protective policies that do not protect these rights, the LGBT population is twice as likely to have two or more mental disorders. Every LGBT person knows as they cross a state line if they are safe there or not. Most people are shocked to even know this and I see that on your face too. When I do presentations I stand up and say can I be fired here? No, everybody says, and as I am telling you, in a majority of states in this country the answer is yes.

Chagpar That is amazing, truly, truly amazing and when we think about all of the work that we do to try to improve care, to try to improve access, the fact is that such incredible disparities exist is just mind-boggling.

Margolies And it goes back to what we were talking about before about increased cancer risks because clearly there is no difference biologically, physiologically, genetically between a lesbian and her heterosexual sister. The increased cancer risks are the results of behaviors, many of which can be traced to coping mechanisms to deal with the stress and stigma of being a sexual or gender minority.

Chagpar Let's talk a little bit about the research that needs to go on because clearly as part of the Healthy People 2020 Initiative the NIH has put out several RFA's to really look at LGBT cancer issues. What do you think are the top key issues that need to be addressed in a robust research way to improve the health of LGBT people?

Margolies We need data, data, and data. If your hospital collected information about sexual orientation and gender identity, imagine what we could learn, and data collection is one of the big things that is being asked for and in the largest national health survey, the National Health Information Survey, we are finally going to have sexual orientation, but not yet gender identity. So we are on the road there, we really are.

Liz Margolies is Executive Director of the National LGBT Cancer Network. If you have questions or would like to add your comments, visit yalecancer-center.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.