

Welcome to Yale Cancer Center Answers with your hosts doctors Anees Chagpar and Steven Gore. 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 could submit 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 LGBT issues and cancer with Amber Anders and Herbert Castillo. They are both first year medical students at Yale School of Medicine. Here is Dr. Anees Chagpar.

Chagpar Could you start off by telling us a little bit about yourselves, your path to medical school and what got you interested in this topic? Amber, how about we start with you.

Anders I was just talking to Herbert about this. I kind of came to medicine from somewhat of a convoluted path. I was interested in astrophysics which does not seem to be too medically related but I started doing research about it and I was always interested in the sciences which led to biomedical research and through that I learned more about medicine and how we can actually impact lives. I really love astrophysics still and read up on it, but biomedical research and the medical end of things just seemed much more tangible and I could really make a difference in people's lives, so that is how I got into medicine.

Chagpar Herbert how about you?

Castillo For me it was a very personal motivation. I was born in Guatemala and at age 11, we decided, my whole family decided, to immigrate to the United States to have a better life, like most immigrants come to this country for, and we had a lot of barriers to healthcare, for example, language barriers but also lack of medical insurance and a lot of other barriers, so for me my early experiences with health and quality has driven me to become a physician.

Chagpar It sounds like both of you for various reasons got into medical school, you are now finishing up your first year, and the whole concept of LGBT rights is a very hot topic and is very relevant I think in medicine, but is not something that a lot of people think about, so how did both of you get interested in that topic, Amber?

Anders I had not done much research related to the topic before coming to medical school, but my brother identifies as LGBT and so through that I was interested in the different medical needs that he had and by working with you, Dr. Chagpar, over the summer, I had the opportunity to participate in research that involved that community, so that was my first time really working with data that had that information which I think we will get into a little bit later. But one of the hardest parts about doing research on this community is there is really a lack of information to even try to study some of the disparities that we see because most surveys and questionnaires do not even address or allow people to identify that part of their demographic.

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Chagpar And Herbert what about you? Castillo I come from a background of doing research and being really interested in contemporary Latino health issues, but I always felt a disconnect between doing racial disparities work and LGBT disparities, there was a very vague disconnect between both populations and I saw that missing link, and I wanted to make sure that in my research I was aware of the intersectionality that a lot of patients have both being Latino and queer, LGBTQ.

Chagpar Let's talk a little bit more about the experiences that you have had and some of the research that you have done and where you think we should be moving the field. Both of you have talked a little bit about disparities, and so I think that is a likely driver, but Amber, you mentioned that some of the research you did in the summer before you started med school was part of a program at Yale called START, can you tell our listeners a little bit about what that is for those who might not be aware of it?

Anders It is an opportunity that Yale offers for first year incoming medical students to participate in research the summer before they start medical school. And I had already taken two years off between undergrad so I was just ready to get here, get my feet on the ground and it was a great opportunity to get research started before school even started and gave me the opportunity to attend conferences and other things. I actually just returned, and I have not shared this with you yet, but I went to the Student National Medical Association Annual Conference two weekends ago and I won best national poster in Social Sciences.

Chagpar Wow! Congratulations.

Anders The poster I presented was related to the part of the project discussing what factors actually go into the patient's decision to disclose their sexual orientation or gender identity with their healthcare provider.

Chagpar Excellent, see I too learn things on this show, breaking news, you heard it here first. Herbert, tell us a little bit about some of the research that you have been doing and how that got started?

Castillo I also participated in the START at Yale summer experience here before the first year started and through that I worked at the Equity and Innovation Research Center at Yale, or ERIC, and there I did a very self-directed project about patient's perceptions of quality of care among Latino respondents and I really enjoyed doing that. I had already done a lot of similar work in my undergrad, so it was just amazing to come here and find that place to do my research.

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Chagpar Let's talk a little bit more about your actual projects and why you chose to look at the questions that you did and what was the driving force behind that and then tell us a little bit about the results of your study, Amber how about you go first.

Anders Starting from working with you, Dr. Chagpar, thinking about cancer and cancer disparities, we talked a lot about the LGBT community and how it is under-researched, not a lot of research right now is addressing the many issues that they face and so the first thing that I thought was important to really ask is, how is this information actually shared with providers in the first place? So before we can even get to HPV vaccinations, which was the next project, we really need to know, is this community comfortable sharing this information with providers? And what factors are related to that? So what we actually found using a perspective web based survey that surveyed close to 600 respondents we had from various LGBT communities across the country, was that some of the most important things in terms of disclosing your orientation was level of education and we found that people that had only completed high school or less were much less likely, about 25%, to disclose that information with their healthcare provider in contrast to people that had at least some college, about 75% of the time they would share that information, so that is just one example of when we are working as physicians and we have patients in our office, knowing their background, where they are coming from, that is one of the things we can use to address some of the disparities we see. Knowing they might identify as LGBT but might not know the importance of sharing this information, and how it can better impact their healthcare. So that was one of the important things we saw and additionally, age was an interesting thing to look at in the study in terms of disclosing sexual orientation. I was not sure which way it would come out in terms of were older people more likely to disclose or not, and what we found is the younger the individual, the less likely they are to disclose. I think that is another important thing to think about as a healthcare provider that provides care for adolescents, teenagers, young adults, they might not be as comfortable disclosing that information.

Chagpar Herbert, your project really focused on quality of care and perceptions of quality of care. Tell us more about that.

Castillo More and more we are finding that perceptions of quality of care reported by patients are a good measurement of eventually health outcomes for them, so in my study, I really wanted to dissect the differences and the variability within the term Latino when it comes to reporting poor quality of care, so having received an event in the clinic that was perceived as poor quality, and I wanted to dissect that because a lot of the time we see the term Latino as a homogenous kind of general term that we then give conclusions to for policy or implications that are going to serve this community but we are not addressing the variability within it, so I wanted to see country of origin because that is a variability that is rarely performed in these data analysis and I found very significant results, for example, Mexican and Salvador respondents are less likely

to have received poor quality of care as opposed to a lot of other nationalities and when it comes to attributing poor quality of care due to their race, Puerto Rican responders are less likely to attribute that to race, so there is a lot of dissection. Unfortunately, the data set that I used which is a really big data set for Latino health

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survey, the 2007 Hispanic Research Center at Robert Wood Johnson Foundation Latino Healthcare Survey, and it does not have any demographics relating to gender identity or sexual orientation, so if I wanted to really dissect that and adjust for sexuality, sexual orientation, gender identity, I was not able to and time and time again, I discussed this with Amber and that is one of the big barriers that we have when talking about LGBT healthcare.

Chagpar And that might go back to Amber, your point, which is some people just do not disclose so even if there was an electronic medical record that could capture this information, and many of them do not, if people do not disclose this information to their doctors, it is really difficult to capture that information and then to potentially tailor care accordingly. Amber this goes back to the question of so what, so what if people disclose or not disclose, how does that affect the quality of their healthcare experience?

Anders One important thing going forward to address, I think in the past there has been a lot of stigma associated with that identification and with that people did not want to disclose because they thought maybe they would receive worse care or no care at all, but I think the field has definitely evolved in terms of physicians that want to be allies, that want to provide this care, I think in our class alone, we have had several sessions on, for example, if you are working with a transgender patient, how to ask them for what pronouns they prefer and things of that nature, so I think we are more equipped to handle these populations as patients. However, the second part of my study looked at HPV vaccination rates and that is one good example; when the vaccine first came out, it was really targeted towards females and with that you would see a herd immunity and the fact that if all females are vaccinated that will protect both males and females. However, that leaves out the whole population of males that identify as homosexual and neither one of the partners have the vaccine, then there is no protection for either one of them, so disclosing that information with the healthcare provider would help to make sure that these individuals are getting vaccinated and currently, standard recommendations are for all males and females to be vaccinated, but we know that women are about four times more likely to receive the vaccine than males and so that it just an overall population thing, but it is especially important for males that identify as gay to get vaccinated because they are not getting that herd immunity or protection and that is one of the important ways that disclosing this information to your doctor could actually improve your healthcare and lessen the risk we see for HPV-related cancers and ideally help address some of the cancer disparities we

see in this population.

Chagpar And certainly HPV vaccination is important both to men and women, whether you are straight or gay. We are going to take a short break for medical minute, please stay tuned to learn more information about LGBT issues and cancer with our medical students today, Amber and Herbert.

Medical Minute The American Cancer Society estimates that over 1500 people will be diagnosed with colorectal cancer in Connecticut alone this year. When detected early, colorectal cancer is easily treated and highly curable and as a result it is recommended that men and women over the age of 50 have

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regular colonoscopies to screen for the disease. Clinical trials are currently underway at federally designated comprehensive cancer centers such as Yale Cancer Center and Smilow Cancer Hospital to test innovative new treatments for colorectal cancer. Tumor gene analysis has helped improve the management of the disease by identifying the patient's most likely to benefit from chemotherapy and newer targeted agents resulting in a more patient specific treatment. 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 guests, Amber and Herbert. Both of these young people are medical students at Yale University and both have taken an interest in LGBT Healthcare in this population. One of the things that we talked about during the break was that we have been using this acronym LGBT quite a bit and yet many of our listeners may not understand that term, the distinction between sexual identity, gender orientation, what is queer, I know Herbert you mentioned that term, can either of you give us a little bit of framework in order to think about this population?

Anders That is one thing I definitely wanted to talk about during this show; we use the acronyms LGBT, LGBTI, LGBTQI, a whole set of letters, however, before I even did this research, I do not think I made a distinction among the group, I just used the term LGBT and grouped everyone into it, a nice pretty box with a bow, which I think everyone likes to do, but there is a lot of variation within this and one of the big things is to tease apart the idea of someone's sexual orientation which is what they prefer, a partner and a relationship versus gender identity and that is more of a personal, how they identify with their gender, and separating those two because they actually have very distinctive medical needs. If you think about someone that changed gender, or they may want to transition or are thinking about hormone therapy, there are a whole different set of needs that those individuals have as opposed to with sexual orientation. There are different needs there, they may be dealing with behavioral or mental health,

especially if there is a non-supportive family or other issues that come with that that the people in this community deal with and I think that is important to understand, that those are very different and different issues come along with both of those that are not always the same and overlapping and so it is nice to use the acronym LGBT but also to think about the individuals and their needs especially the healthcare side, that is important.

Chagpar Herbert, do you want to talk a little bit about this other term that has now been thrown into the mix, queer, many people may think that they do not want to use that term because they feel that that might be a slur.

Castillo I feel like queer is a term that has been reclaimed by a lot of activists throughout the LGBT movement and I feel like queer can be a very broad term that can include a lot of people and not necessarily describe a lot of the experiences, so a lot of people that are identified as queer do not

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necessarily want to be boxed in the label of gay or lesbian or bisexual, I think that is also coming from an understanding that sexual orientation and gender identity are also very fluid, so I think it is more acceptable now-a-days to self-identify as queer.

Chagpar We talked a little bit before the break about disclosure and the fact that many people do not disclose and one of the issues is we are trying to unwrap the medical issues associated with this population. Often we do not know who this population is unless we have that conversation, so how do you recommend that healthcare providers start that conversation or conversely, how patients might disclose without feeling uncomfortable, have you thought about that?

Anders I actually have and being first year med students we have been learning the process of just taking a proper history and honestly, there are lots of parts of taking past history that are uncomfortable, you ask about many things in a person's life and I think the most important thing going into it is just do not make any assumptions, do not just assume that someone has a wife or that someone is married or any of those things, just go in without any assumptions and honestly we are all humans, I think having a conversation with an individual and making them feel like it is a safe space, I think, is the most important thing. One thing I have seen interacting with people in the community is usually there are maybe one or two go to general practitioners in a particular community and the entire LGBT community in that city will go to those one or two and my hope would be to expand that and not just burden these one or two individuals with the whole community and really have more physicians be on board to help and be advocates and allies and feel comfortable treating LGBT individuals and feeling that they can properly assess the care that they need, so that is my idea, hopefully going forward, to expand, and not just burden one or two doctors in the entire city with all the LGBT community. Having fluid and open conversations with no assumptions and definitely creating the safe space especially for

younger people that do not unnecessarily disclose or feel comfortable, is key.

Chagpar Herbert?

Castillo And I think also understanding the positive outcomes of disclosure as well. We have not really talked about how cancer affects LGBT individuals but they are in a unique position. I am reflecting back about learning the differences of outcomes of prostate cancer between a heterosexual male and a male who had sex with other males, so in that case, we can tease apart how different prostate cancer can be for a man who has sex with other men because we know that it is going to affect his sexual functioning in a very unique way that it is probably not going to affect the heterosexual man, so if that disclosure is not made, I feel like all that intricacy that we can explain to that patient is going to be lost and we really need to make sure to outline that disclosure is going to bring about positive health advice and really support for LGBT patients.

Chagpar I could not agree with you more. Amber, you mentioned a little bit earlier about transgender individuals who are making a transition and the use of hormones that can help you to do that and

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how hormones really affect your cancer risk, so again, disclosure is really important and I think that there are a lot of ways for healthcare providers to kind of give people the signals that they are open and welcoming, whether it is having a rainbow flag in their waiting room or being on the list of LGBT Leaders and Healthcare from the Human Rights Commission, I think it certainly is really important. Amber, what do you think are still the burning needs for this population, what works? Clearly there is much that needs to be done in terms of research and moving the field forward in a population that has been understudied. What do you think are the burning platform issues that we need to address?

Anders One thing is, as I mentioned before, that there used to be a lot of stigma in a negative sense I think that was perceived in the healthcare field, but now I think it is more so people are afraid of the unknown and not sure they can provide adequate care, so I think it is just giving, especially medical students, early in our education proper tools to help these individuals is really important and honestly I think the power of the media even though we are talking about medicine and healthcare, one person I talk about all the time, Laverne Cox, she is on a popular Netflix show and has had a great career so far as an actress, but she has really come out at the forefront as one of the leading voices for transgendered individuals. This week she was named in Time Magazine's 100 Most Influential People of the Year and having powerful role models like that for individuals is great. When you are not in a large city with lots of resources, you can feel very isolated, and I think with the power of the internet and the media, having people like her on the covers of magazines and speaking at different events can be very powerful in just transforming our society as a whole, and I

think that will hopefully spill over into healthcare and dispel some of those other stereotypes that have existed, and so I think using those things, the advantage of having speakers like her speak more towards healthcare needs and issues would be great.

Chagpar How about you Herbert?

Castillo I think coming together in your professional networks and discussing this. Recently in my professional network, the Latino Medical Student Association, along with the National Hispanic Medical Association and other Latino health organizations, came together to write up a resolution looking at the discrimination of Latino LGBTQ patients and also having clear concrete steps that are going to bridge those gaps that we have, those disparities that the Latino LGBT patients still experience.

Chagpar I think the role of celebrity and the role of making sure that we address these disparities is so critical, even if we take a step back from transgender individuals, but right now the political attention that is being paid to gay marriage and gay rights is so powerful and due a lot to celebrities who have come out and said, you know what, I am gay, I am lesbian and I am human and deserve the rights of everybody else and when I am sick I want my partner to be there with me. It is so critical for what we do in terms of patient and family centered care no matter how you define your

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family. Tell me a bit more about where you are taking your research and where you think we need to focus in the coming year, I mean both of you as first year medical students have done phenomenal work so far, I mean it is your first year and the first year is not even over yet but where are you going to take your research, Amber?

Anders I am actually participating in a program at Massachusetts General over the summer and it is going to be looking at endometrial cancers and actually Herbert and I again were having this conversation before, and we are both going to be using a similar database, the SEER database looking at cancer and so mine is actually looking at cancer disparities in the Latino population for females with endometrial cancers and I ran into the same problem, I would love to do the same analysis looking at LGBT communities but the data is not there and so I think one of my things going forward I really want to advocate for is getting this demographic information onto more surveys and questionnaires because I think that is one of the reasons we see the disparities that we do because proper and adequate research just cannot be done because the information is not even there to work with, so hopefully still doing my project at MGH, but also trying to see if I can work to get that incorporated into some of these databases and go from there would be ideal, but I really want to advocate for trying to get this information out there and then on the tail end of it, get people that are

getting these surveys and questionnaires to feel comfortable with sharing that information so it is a kind of a two sided platform that I want to achieve.

Chagpar Great, and Herbert?

Castillo I am going to be sticking around here for the summer. I am going to be working at the endocrine section at the surgery department. I am doing again database analysis, and SEER is the most comprehensive repository for all this data, so the fact that SEER does not have this is really limiting our analysis. I am going to be conducting thyroid cancer surgery refusal analysis, so I wish I had that data too.

Chagpar Because it certainly may influence how patients perceive their health-care experience. The good news for both of you is that the National Health Interview Survey, we hope, will be including at least some measures of sexual orientation in the upcoming surveys, the NHIS is the largest repository of health information but unlike SEER, it really does not drill down into cancer information which is so important and certainly what many of us have used to try to tease out some of these epidemiological trends. I guess the other question is, how do we start looking at the biologic implications of people's gender orientation, we have less than a minute left, but Amber any final closing comments and Herbert in 30 seconds what you want our listeners to remember.

Anders Going forward I really want to help address the disparities that we did not really go into great details on, but the disparities seen in the community that exist and LGBT communities, there are a lot of issues to be addressed there and I think we need more people like Herbert and I that want to fight for this and research this and make it important and I think institution supporting that is the greatest thing. We need more institutional support in doing this.

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Castillo And just understanding the intricacies of LGBT queer life and also creating more action oriented research that has implications for health outcomes for this variable number population.

Herbert Castillo and Amber Anders are first year students 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 format 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.