



Speaking About Breast Health As A Family

When Estela gets diagnosed with bilateral breast cancer she opens up about her health and body to her adult children in ways her Mexican mother never did with her. And Laura Fejerman, a researcher studying hereditary breast cancer among Latinas, speaks with Juleyka about how to talk with older relatives about their health histories and private parts without making them uncomfortable.

Juleyka Lantigua:

Hi everybody. Today we have Estela with us. Growing up, Estela's, Mexican parents kept conversations about their health and physical bodies, very private. She doesn't even remember ever actually seeing her mom naked. As an adult, and after receiving a painful diagnosis, Estela realized she had to do things differently with her own kids. But doing so was still a challenge. Let's get into it.

Estela:

I'm Estela Casas. I am the author of *A Place to Anchor: Journalism, Cancer and Rewriting Mi Vida as a Latina on the Border*. My background is in news. I was a broadcast journalist for 37 years, first generation El Pasoin, and proud of my heritage.

My parents were a lot older than me, 41 and 49 years old when I was born. So I didn't get to know my parents very well, but I always called mama and papa and I wish I'd had the opportunity to get to know them a little better with conversations that we should have had.

My parents, when they came here to the United States, they came from Mexico. We didn't have a lot of conversations about health because it was always very hard for them to open up because probably a lack of education and a lack of exposure to a lot of things.

I would've learned more about our families, our background, our medical conditions. Come to think of it that my mother had had a cyst, a cystic sarcoma removed from her breast, but didn't have any chemo, didn't have any radiation, so we never talked about it. So until I got it, I realized that I had some sort of background of cancer in my family. So now going ahead with my children, I have all kinds of conversations with them that I should have had with my parents.

In 2010, I was diagnosed with thyroid cancer years after my mom and dad passed away, and I'm the one who found a four centimeter lump on my neck. It was the

size of a walnut. And 2017, seven years later, I was diagnosed with bilateral breast cancer. So that means it happened at the same time. Stage one on my right breast, stage two on my left breast.

I was at home by myself, and when I heard, "You have cancer in both breasts and we're going to have to remove both breasts." I mean it's devastating. Informing my family about my diagnosis was tough enough. How are they going to feel? You just never know what's really going through their heads. I have three kids, my daughter and my two sons. My son was 13 years old, in middle school. My daughter had just gotten a new job and my son was going to start his doctorate in physical therapy. I had just gotten divorced and I had started dating and there was just so many things happening in my life and then this, I cried. I cried. But then I'm an independent woman and I believe in action and moving forward, they would see me cry, but they wouldn't see me cry when I cried at night. This journey brought out some things that we hadn't discussed before, and being so open about it was a difficult conversation to have with my children.

As a woman, I think we have to be strong for everybody. You got to be strong for your kids because they're always watching you and you want them to be strong as well. I had really never allowed myself to be vulnerable, but there's nothing more vulnerable than talking about your breasts and how you're going to lose them. It's like, who talks about breasts? I mean, we never talk about breasts. Everybody sees them, but you never talk about them. It was taboo to talk about your private parts. When I saw my mom's body really for the first time was when she was 80 years old and I had to bathe her. I would see her arms when she wore short sleeves or her pretty legs when she wore her hose. But everything else that was covered up I had never seen. Unlike me showing my breast to my daughter and she's seen me naked and she's seen all of those things.

I never saw my mom and until she was very sick, that was the first time I ever noticed her breasts or noticed her body. That was a very painful moment because I felt that she was very embarrassed for me to see her. And it was just something very hard for both of us.

This diagnosis, I think, showed my children how strong I am, but at the same time, they've seen my scars. A strong mother who has always been the disciplinarian, but now they've seen the mother who is vulnerable and has suffered. It certainly makes me more human.

February 21st, I will mark my five year that I can say I'm in remission, but every day it's not a matter of if the cancer is going to come back. It's a matter of when these conversations don't end like cancer doesn't end. And I'm very well aware of that.

Lantigua: I relate so much to Estela's story. I'm a mom, I'm a daughter, I'm a sister. I mean, her experience made me think so hard about how difficult it is for so many first gens to talk about our bodies and the bodies of women in our family, feelings of shyness, shame, and even a desire to protect our relatives. All of that makes it really easy to avoid the subject completely. But these conversations are necessary and often they're actually urgent because they can keep us and our loved ones healthy and safe. So how do we break this taboo to help us figure it out? I called in an expert.

Laura Fejerman:

My name is Laura Fejerman. I'm originally from Argentina, professor in the Department of Public Health Sciences at UC Davis and associate director for community outreach and engagement, as well as the director of the Women Cancer Care and Research Program. I do community outreach and engagement and education, navigation focus on Spanish-speaking Latinas. In particular, I'm interested in identifying breast cancer and how our Latinas understand genetics and their family risk, and we're trying to help get more women screened for genetic predisposition. And on the other side, I have a lab and I do genetics of breast cancer in Latina trying to discover new predisposition in our genomes.

Lantigua: Wow, that sounds like you need a superpower to do that kind of work.

Fejerman: I would call it patience.

Lantigua: That's a superpower.

Fejerman: Exactly.

Lantigua: All right. So easy question. As you listen to Estela's story, what did you hear?

Fejerman: I found it fascinating, partly because I identify with her in many ways. My mom was very similar to what Estela says about her mom. On the more scientific reaction, a lot of the things she share are things that we are hearing when we do our work in the community, which is related to the types of relationships that some of us in our Latino community had with the older generation. A little bit of that idea that it's a mixture of shame, trying to keep your body very private or being ashamed, not wanting to share that, to worry your kids. There's different things like that. And I also heard the part where she tries to be very different from what she had with her mom, with her own kids.

Lantigua: Yes, she is definitely aware of the disadvantages that she experienced not having any real sense about her mom's health history, not really understanding potential repercussions for herself. Tell me a little bit about what you've learned in your work as far as the challenge of overcoming how do people overcome these

cultural barriers? How do people overcome these taboos about our health, about our bodies?

Fejerman: I think that the secret is education, but tailored to the community values of the group you're trying to address the issue for. And for example, with the study *Tu Historia Cuenta*, which is the program that we have to educate Spanish-speaking Latinas about hereditary breast cancer, part of it is we use community health educators to reach out to the community and they use their own language, and their own emotions, and relationships, and histories with these issues when they educate the community. So we have a story as part of the program. So we share information through the story of Mariana, and we tell the story of how she found the lump and what happened every stage, every part, and how she ended up having to talk to her daughter and her daughter got tested. I think that is really important in any education program that you do is find a way to tell a story that resonates with people. So you're not only sharing information about DNA or what a mutation is, and that the more concrete, scientific knowledge that we want them to have, but also that they see themselves in the story. They can relate to what happens to Mariana, for example, where she feels scared, she's unsure of what to do and she doesn't have insurance, and who's going to cover it?

Lantigua: Do you find that women like Estela who are the first generation daughters are helping to break some of these taboos and barriers, and how are they accomplishing that?

Fejerman: Yes, I do. I think they are. I have students that come to do internships with me, and the reason they come, they are first gen Latinas and they come to me because they had family history and they hear about these programs and it resonates with them. And we have a teen program, it's called Teens for Screens, and it's college students going to high school students to teach them about breast cancer. And the idea is to have this younger population of high school students because they are in the home, they haven't left the house yet to establish these relationships around cancer health.

Lantigua: So one of the things, I'm a mom also, and I really understood when Estela said that through her own suffering and through discovering this massive condition, she still wanted to protect her kids from suffering, from being hurt by what she was going through. What is your advice for moms, and women, and daughters who might be caught in that contradiction of I'm the one experiencing this horrible thing, but I still have this impulse to protect my loved ones?

Fejerman: I think all parents have that instinct, especially when the kids are young, we start sharing. I think when they get older and the kids go like, "You went through what? And you didn't tell me before." I always tell the kids, I train kids, young adults or adolescents on breast cancer prevention, and I always tell them that it's important

that they start conversations and ask the parents, "Have you ever had a mammogram?" Start by sharing what you learned. "Oh, I learned this amazing information today when I was doing this program, and it made me think that you're more than 45 or 50, and it's time for you to get a mammogram." In a way, show your parents that you're ready to hear this information. It's preparing our youth to show us that they are not that vulnerable, that they can take it and they can support you, and that it's not your own burden because they care and it's not for you to carry alone.

Lantigua: So for those of us who are older, I'm in my mid-forties and similar to Estela, I don't think I've ever seen my mother any part of her body other than her legs and her arms. How do I even begin to have a conversation about something as intimate as, have you had a GYN exam? Have you had a breast exam? How do I do that without seeming to be disrespectful, without seeming to be inappropriate? Now I have a fear that if I don't start the conversation, maybe no one will.

Fejerman: A good way to start is always to create a space for a conversation first. And so finding that moment where you can say, "Mom, this is going to sound weird to you, but I want to have this conversation that it might seem uncomfortable, but it's coming out of my love for you. I want to ask you a few questions, do you mind?" You do that before they know what you're going to? They'll be surprised and they'll look at you-

Lantigua: And suspicious.

Fejerman: ... And suspicious, but they'll likely say yes. And then you can say, "I've been reading." You know, share that your concern comes from some new knowledge. "I've been reading about this and it made me wonder..." Or "I heard this clip about Estela, it's the story of this woman that had a mother..." Just share something that makes you start from "outside." If you have an outside story and then you go into your own story with your mom.

Lantigua: And if she says, "It's none of your business."

Fejerman: I know.

Lantigua: Because I can guarantee you that is exactly what she's going to say.

Fejerman: We practiced that with some of the students we did improv for difficult conversations with, and we practiced one with a grandma that the student said, "My grandma is like, get away from here. That's not of your business. You little kid."

Lantigua: Exactly.

Fejerman: And sometimes humor or when they say, "It's none of your business" you can always say, "Well, in part, it is because some of these things I can inherit as I've

learned, there's some genetic predisposition. So it's very important for me to know, you know how you're doing. I have breasts too. And in a way, your breasts and my breasts are connected."

Lantigua: Exactly.

Fejerman: I mean, it could be that they push back and it might take a few times, you know, have to be very patient and say, "Okay, it looks like today is not the day, but I'm going to keep trying, mom, I really want to have this conversation."

Lantigua: All right. My final question is about folks who have never started this conversation who might not even understand themselves, how something like cancer works. What recommendations do you have for places that are trustworthy and reliable for information in English and in Spanish so that they can get some of the medical processes and terminologies down in case the conversation goes well, and Mom is open to receiving information and guidance?

Fejerman: Luckily, there's so much out there, but I would say reliable sources would be the National Cancer Institute, English and Spanish. The American Cancer Society. They also have tons of information of about breast cancer, [inaudible 00:17:01] breast cancer, sporadic breast cancer, other cancers. And for breast cancer in particular, there's also Komen foundation. And for, there's an organization called Force specific for hereditary breast cancer. And on their website, they have really, really good information and even information about support groups and what to do and navigation.

Lantigua: Wonderful. Laura, thank you so much. You have been a treasure.

Fejerman: Very happy to be here, Estela's story sounds really inspiring.

Lantigua: I hope that this episode helps a lot of people get the conversation started, get themselves and mom checked, learn your history. Thank you. Thank you.

All right. Here's what Laura taught us today.

Start with a story, when broaching the subject of bodies, private parts, and physical health with relatives. Don't just go straight to the data. Okay? Talking about a personal experience first can help you connect and build intimacy, which will hopefully make everyone feel more at ease.

Point out the awkwardness. If this is the first time you bring up this topic with your family, it's probably going to be weird. Pretending otherwise will only make it worse. So acknowledge the potential for discomfort explicitly, and go from there.

And remember, make it your business. If your loved ones feel your questions are intrusive, explain that because of genetic factors, knowing about their health and about their body can help you better understand your health and your body.

We have linked to some of the resources Laura recommends in our episode notes. Thank you for listening and for sharing us. *How to Talk to [Mamá and Papí] about Anything* is an original production of LWC Studios. Virginia Lora is the show's producer. Tren Lightburn mixed this episode. I'm the Creator, Juleyka Lanitgua. On Twitter and Instagram, we're @TalktoMamiPapi. Bye, everybody. Talk to you soon.

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