



Podcast Transcript

Beyond Pink Ribbons: One man's fight with breast cancer in America

Featuring Nilton Fonseca

Dispatcher: 911, what's your emergency?

Caller: America's healthcare system is broken and people are dying! (ambulance siren)

Welcome to **Code WACK!**, where we shine a light on our callous healthcare system, how it hurts us and what we can do about it. I'm your host **Brenda Gazzar**. This time on **Code WACK!** What unique challenges do men with breast cancer face when it comes to health care? How do insurance companies make getting certain tests more difficult for some

cancer patients? We recently spoke to Nilton Fonseca, a husband and father of three from the Greater Los Angeles area, who was diagnosed with breast cancer in 2020. He's an engineer with more than three decades of construction project experience both domestically and abroad

Welcome to Code WACK! Nilton.

Fonseca: Thank you for having me.

Q: Thank you so much for being here. You are among the roughly 2,600 men in the United States who are diagnosed with breast cancer each year. Since less than 1% of breast cancers happen in men, that must have been quite a shock.

(1:01):

Fonseca: Yes, yes. It was a very, very big shock because I never imagined in the remotest of possibilities that this is something that could have happened to me because I've generally been very diligent and conscious about my health, having regular annual checkups. No matter where I was in the world, even when I was living in Asia, I made a point of getting thorough medical checkups, and I, you know, had no history in my family from both my dad and mom's side of any cancer at all, so I never imagined cancer ever striking me.

Q: Right, and so how were you diagnosed?

(1:34):

Fonseca: It started out as a dull pain on my chest, on my right breast. It started possibly in 2019. This was the middle of the year, more or less down in the summer. The pains started out, the dull pain ebbed and flowed and then towards the fall of 2019, it was typically on weekends. There were

some of the weekends when I felt more of the pain. And when I look back, it's something that, because I was very busy with work back then, life was going at a hundred-plus miles an hour, it never really occurred to me to pay more attention to my body, to what my body was saying. But there was a couple of weekends, two weekends in a row, where I felt these intense, pangs of pain in my chest and specifically the second weekend after that, I ended up going to an urgent care to have it checked out.

And the attending physician then examined me, did a physical examination and he determined that I had what felt like a small lump on my right breast and then he referred me to the Women's Imaging Center for a mammogram and an ultrasound, a breast ultrasound.

Q: Wow. Interesting – to the Women's Imaging Center?

[\(2:42\):](#)

Fonseca: Yes. Men don't typically get tested for this kind of condition and even family doctors don't typically talk to men about examining themselves or checking their breasts for lumps and, you know, so locally where I live in the Redondo Beach-Torrance area, there's an imaging center. Yes and, and that's the name. It's called Women's Imaging Center. <laugh>

Q: Wow. How did you feel being referred to the Women's Imaging Center?

[\(3:06\):](#)

Fonseca: Well, it felt a bit weird, but I knew that, you know, it was just a name. The machines are all the same, whether you go for an MRI or an X-ray machine. They don't discriminate against sex and I knew that I had to do it because it is something that I never like to, you know, leave and not

be intimidated by it. It's something that I see it as almost like a beast and I gotta face it, face that fear and I wanted to get it done as soon as possible.

Q: Hmmm. Right. Right. Well, I'm so sorry you went through all that. What distinct challenges did you face as a man dealing with breast cancer when you were being treated, for example, did you feel like the programs and support services met your needs?

(3:46):

Fonseca: The only thing that I saw that was really more oriented towards women was actually at the Women's Imaging Center – the forms that I had to fill in when I got there, including my medical history, that was more geared towards women where it asked questions such as if you're pregnant or when did you have your last period, or when did you have your last mammogram? And obviously you don't see many other men there and also because this happened during the pandemic. It was in March, although just backtracking a bit when I went to the urgent care center for that pain was back in from memory around November. And then I tried to schedule an appointment right afterwards. It was also, I had some issues with getting the insurance approval for that, because they approved for one breast.

And then the imaging center then, you know, contacted the doctor again, saying no, it's going to be two breasts, you know, examining two breasts. So I had to get that reapproved then I was ready to schedule. Then it was like at least a 3-month waiting period. And then at that point in time, I had to go out of state for work and the pain coincidentally sort of went away and, you know, so I was out of state. It was only due to the pandemic when everybody then had to come back home and work from home that I then, you know, managed to get an appointment scheduled and I went in, as soon as they had availability and that was in March, late March. And at that time, yes so people were not allowed to have any other guests with them. It

was just individuals going in. I think I was the only male on that day in that center. The rest were all ladies there waiting in the waiting room as well.

Q: Tell me more about working with your health insurance company. You mentioned you had trouble getting your insurance to pay for your mammogram?

(5:21):

Fonseca: Because they had only approved one breast. What the imaging center later told me is that typically these are done on two breasts and I think by default, the insurance company only approved one side. So that was a challenge in itself. The mammogram took a bit longer than necessary because when you go through an HMO, everything has to be pre-approved and because this is out of the routine, it's not a system-approved procedure. It has to be looked at by a real person <laugh> maybe a medical director or something has to review it for medical necessity and he or she then has to approve it and then if for whatever reason, once it's approved it then goes to the imaging center, then the imaging center (says) 'Nope. It's not correct. You need to also get the other breast approved' <laugh> so then you go back to the beginning of the line again, and then wait.

And then sometimes it can't really be modified right away. That's per my understanding. It's the original physician who entered in the referral request in the system has to log back in and, you know, resubmit again, resubmit the request again. But I think after I was diagnosed with cancer, some of these approvals in terms of the surgery itself, the breast surgery and the MRI following it, that was approved relatively quickly because I was diagnosed also with infected lymph nodes.

The cancer had spread to my lymph nodes because I had a lymph node dissection. And there was about from memory about 12 lymph nodes

removed underneath the armpit because typically the breast tissues, when they drain in the lymphatic system, they drain the sentinel nodes below your arms and out of those because the cancer had spread to the lymph nodes, the indications were that I had to have chemotherapy and per my understanding each patient before they undergo chemotherapy, especially due to breast cancers, there is a genetic test, which is typically done.

It's called the Oncotype DX. Those typically are routinely approved, you know, so that the oncologist can then sort of plan out the chemotherapy drug cocktails that you end up taking. But in my case, it was rejected on the basis that there's not enough data on men to justify this test being approved. So we appealed that and they rejected it. And so it's one of those chicken and egg things. If you don't test enough men, you don't get enough data on men. So in discussions with my oncologist at that time, she mentioned to me, 'look, you know, let it go.

(07:43):

We'll just go on a more conservative treatment approach in terms of chemotherapy.' So I had, you know, to start chemotherapy right afterwards. It was around after I was healed enough, I had my surgery literally 20 days after the diagnosis and then I started chemotherapy about a month after that, after I was well enough to go back in, because I had to go back into (Operating Room) to also get a chemotherapy port implanted into my chest. So that's where they inject chemotherapy. They try to avoid going through your veins, through your arms these days so as to not damage the blood vessels in your arms. I started the chemotherapy right there in May and that lasted until the end of the year.

Q: 2020. Right. How did you feel, Nilton, when the insurance company didn't want to approve this genetic test for you?

(08:32):

Fonseca: Very, very disappointed. <laugh>. I'd say a bit angry in the beginning, but anyways, my oncologist calmed me down. She said, 'look, it's fine.' She said 'we know you have to do chemotherapy, so you'll have to let it go. Just focus on your health.' And at that time I was, I think I made a conscious decision as well not to dive too, too deep into the different types of treatments and what ifs and whatnots. Maybe taking a little bit out of you know my career playbook is I approached this as almost like a project. And I said, 'okay, it's a project and I need to see it through to the end.' And I was just focused. Okay, gotta get through the chemotherapy and then after that, yes, I was disappointed because I do know that they are, they're in the business of making money ultimately. So if they can reduce cost, so be it.

(09:21):

Q: Right, right. Wow. How are you doing today health wise?

Fonseca: My cancer is in remission thankfully and right now I'm just on regular call it surveillance protocols with the oncology team. I see my oncologist every three months and my radiation oncologist once every six months. I actually just had, you know, appointments with both of them in these last couple of weeks. I'm also on maintenance medication now for at least five years. It's a hormone therapy that I'm taking so luckily for me, it's not giving me any side effects because the medication I'm on sometimes do give some of the women that take it and even some men menopause-like symptoms. So for me, I've been blessed in that respect. I haven't had any adverse effects from that medication. It's something that I'm on now for at least the next five years to prevent the cancer from coming back and now also, since I've had the cancer, I now have to have a mammogram done at least once a year on my healthy breast that I still have.

Thank you, Nilton Fonseca. Tune in next week to hear more of Nilton's story and why he supports Medicare for All.

Do you have a personal story you'd like to share about our 'wack' healthcare system? Contact us through our website at heal-ca.org.

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