



Culture and Healthcare: Two Sisters Empowering the Hispanic Community

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Breast Cancer Survivor

Jennie Santiago:
Co-Director of LatinaSHARE

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Shirley Pacheco:

When I was going through treatment, I also had a double mastectomy and reconstruction. When I was going through treatment at my hospital, I became more familiar with the same hospital but in a Hispanic community. What I found is the treatments that I got at my hospital versus the treatment that women got at the Hispanic community hospital—very different. I found that it is a problem with culture.

I think, it is the problem of lack of communication between doctors and patients and their inability to connect with that culture. The cultures of Hispanic people are slightly different. Everyone thinks of cancer as death, but Hispanic women, that I have found, are fearful of asking questions. They do not question authority, and they see doctors as authorities.

They are not educated. I deal with some illegal aliens as well, so they are fearful—fearful of going to the hospital for fear that immigration is going to be called. So I found that women need to be more empowered. That is why I started working with them.

When Jennie was diagnosed, I think I was in shock, because I always thought it would be me. I always had problems with my breasts. Jennie was diagnosed before me, and she is actually number five, on the maternal side, to get breast cancer, I am number seven. So I think her breast cancer hit me harder than my own.

I tell them, this is your body. You have to speak up. You have to be your own patient advocate. You can't just allow other people to make decisions for you. You have to do research, you have to ask questions, and you have to do it with positivity. You can't have this doom-and-gloom attitude, where you think, why ask because my life is over. A lot of times, that is their attitude. I am going to die.

They have to realize that we have come so far with the types of treatments that we have, that longevity is much better more than it was years ago. I always encourage them to speak their mind, ask questions, not be as fearful as they have been taught to be about cancer, and to try and look at it with positivity. Try to find the positive.

I found the positive in it, because I have great breasts, so cancer is not what you want to go through. But you have to try to find some positive in it and have faith that you are going to get through it.

They deserve the same type of treatment, the same type of compassion that anyone else deserves. For me, it goes back to the lack of communication with doctors, the doctors not being able to associate with the type of culture that they are dealing with, and not being trained to deal with that culture.

Jennie Santiago:

We have many Hispanic women who come to SHARE and join our support groups throughout New York City. What I do in our support groups is we empower them to be the best kind of patient there is, be active in their medical care, be able to ask questions, be able to do some research on their own. In our support groups, we provide a lot of educational opportunities for them, as well as in the SHARE programs.

They come to us as a point in their lives where they feel there is no hope. They come to these support groups, they get the emotional support that they need, and the education as well. That makes them a much better patient.

We have, at SHARE, the survivor, patient navigator program, of which I happen to be a certified trained survivor in that navigator program. I am in a New York City hospital, St. Luke's, and my position there is to work with the breast surgeon. At the time of diagnosis, I am the person in the room with the surgeon, and I deliver that diagnosis to the patient in Spanish.

I explain the diagnosis. I explain what the treatment plan is. And afterwards, I take them out of the exam room and bring them into our library, and I give them more information and tell them my story. I have been through it, and it is very important to talk to someone who has already been through it already.

Well, I think that coping comes from the type of person that you are. I am a strong person. I always have been and positive. And I didn't see a breast cancer diagnosis as impending death. I said, this is a time for me to fight, if anything.

So I went to a support group for the first time, and I noticed around the table there that there were women there from other countries. They didn't speak English. They could not communicate with their doctors. They had no insurance. They left their families behind. They were all alone.

And I sat at that table and I said, oh wait a minute, I don't need help. I need to help these women. And that's what I did. I asked my facilitator "What can I do to help these women?" I have the benefit of language. I have great healthcare. I have a great support system in my family. I don't need this. I want to give to them. And that's what prompted me to get into this. And one thing led to another, and I found SHARE. And I took lots of trainings, lots of education, lots of certifications. And here I am. I went from being a support group member to being the co-director of their LatinaSHARE program, which is incredible to me, because this is what I do. I want to educate women that cancer is not a death sentence. There's a lot of life after that and a lot of education to be had.

We work together a lot. We collaborate. I tell her about conferences. We do things together. She has a great support group, and she's a wonderful facilitator. Maybe it comes naturally. Maybe it's because we've seen so much cancer in our family that we haven't seen any other family member become activists—just the two of us.

I particularly like being an advocate, because it has given me the opportunity to go to Washington D.C. many times and actually speak to our elected officials, congressman, and talk to them about my cancer experience and how important it is to have funding for cancer research.

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