FILM TRANSCRIPT
For Ourselves, For Our Families: Genetic Cancer Screening in Latina Women

Speakers:
1. Jessica Kent, cancer genetic counselor, Cancer Risk Assessment and Prevention Program, Women and Infants Hospital
2. Dr. Trevor Tejada-Berges, gynecologic oncologist, Women and Infants Hospital
3. Dr. Pablo Rodriguez, clinical assistant professor Brown University’s Program in Medicine, Founder and Chair of Latino Public Radio, talk show host, “Nuestra Salud”
4. Barbara Johnston, BRCA positive patient
5. Petra Cintron, health promoter, Chispa, Rhode Island
6. Melanie Wasserman, PhD Health Policy and Administration, MPA
7. Isabel Pestana Neighborhood Health Plan Rhode Island and Latino Cancer Control Task Force
8. Ericka Moore: Neighborhood Health Plan Rhode Island and Latino Cancer Control Task Force

Introduction

Jessica Kent: We do know Hispanic women are receptive to learning about hereditary cancer risk and the option of genetic testing if offered these services in an optimal setting.

Petra Cintron: Many young women are dying of breast cancer. In fact, many women have breast cancer and don’t even realize it.

Isabel Pestana: We want to be prepared for things in life – in general, you don’t want to go on a trip without your suitcase, so you don’t want to go through life without having these tests that will better prepare you to face potential situations in your life.

Melanie Wasserman: You might be concerned about cancer screening today if you’re a Latina woman, for example, but you might also have a lot of other things that you need to deal with. Until those needs are addressed, you might not be able to think about cancer screening.

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Dr. Pablo Rodriguez: Hello this is Dr. Pablo Rodriguez here, like every day bringing you the most important news about your health: physical, mental, political, economic and universal health here at Latino Public Radio. Better than the one The American Congress will provide. We are located at 407 East Avenue in Pawtucket, at the Women’s Care main offices, where our community is born. And today I wanted to about these confusing blood tests that help determine the risk of developing breast cancer specifically. One in every eight women will develop breast cancer every year in the U.S. We are talking about a pretty common illness. This is of concern to all women especially for women who already have a family history of breast and/or ovarian cancer. These women may benefit from genetic counseling, which may include testing for mutations in the BRCA1 and BRCA2 genes. And I asked whether everybody should take this test and the answer is no. Only about 10 percent of breast cancers are inherited. The majority of women who develop breast cancer do not have a hereditary form of cancer, however, those who fall in the 10 percent for this risk should do the test and be identified in order to receive preventive interventions. And many of these women will develop breast cancer in their younger age. In other word, it is important to identify those women who are at risk.
Approximately 1 in 400 women in the U.S. carries a BRCA mutation. Up to 30.9% of high risk Hispanic families have been found to carry BRCA mutations.

Jessica Kent: I think it’s very important in cancer genetics to identify these high risk patients because in these families that do have a cancer predisposition, the risk of developing these related types of cancers is much higher than it may be in a family where we are seeing some cancer history but not because of an autosomal dominantly inherited gene mutation. In these families, being able to identify these high risk patients allows us to tailor their medical care to their level of risk.

Barbara Johnston: The doctor gave me the options, and I think that’s good, because he didn’t say you should do this or that, he told me the options were and what other women have done. He told me that I can think about it, and I think what I chose is the best for me, I don’t know about for other women.

Jessica Kent: The BRCA test which is sometimes referred to as the BRCAnalysis, is a blood test designed to analyze two specific genes, BRCA1 and BRCA2. “BRCA” stands for Breast Cancer 1 gene and Breast Cancer 2 gene. In some families, there are mutations or changes located in these genes which knock out the function of that gene. In these families, because of the presence that mutation, there can be a much higher hereditary risk for both breast and ovarian cancer. The risk for breast could be as high as 87%, and ovary risk over the lifetime can be as high as 44%. So it’s very important to identify these high risk families and to offer genetic testing when appropriate, so that we can the most appropriate screening for these families.

Isabel Pestana: We do talk about BRCA testing as well as trials, testing for Latinos in general. It is important and how can it not be. It is definitely a preventive measure that Latinos and all Rhode Islanders should be getting used to and following up with this. Is it being done – I’m not sure – to the extent that we would like it to be, especially in Latinos.

Petra Cintron: Latina women will benefit from this study because we don’t have information about whether we are at risk to develop cancer, and if somebody in my family has died of cancer, I don’t know what my risk is. So this would be a good way to know if I am able to cure my cancer.

Dr. Pablo Rodriguez: This genetic mutation in the BRCA1 or BRCA2 genes creates a syndrome whereby people are at greater risk of developing certain types of cancers, particularly if they already have a significant family history. And breast cancer is the most commonly detected cancer among Latina women. So it is very important that we learn about this.

TEXT: About 56 to 84% of women with BRCA mutations develop breast cancer. Current guidelines recommend that women with significant family histories of breast and ovarian cancer be referred for BRCA genetic counseling.

Barbara Johnston: I remember when I was a little girl, my mother always used to say that if we felt something in breast, go to doctor. Her mother died when she was 30 and it was from breast cancer.

Petra Cintron: Actually, my family never told me whether anybody in my family had died from cancer. For my family, it was taboo to talk about it. In those days, people didn’t discuss if somebody had died from cancer. I don’t really know if there is anybody in my family that died from cancer, especially on my mother’s side because I was raised by my father and my grandmother. Now that there is so much
information available on television, on the radio, you can pick up pamphlets in the hospital...this information wasn’t available so readily in the past.

Jessica Kent: The reason why we always like to start with an affected family member first is that if we’re able to test someone with breast or ovarian cancer or a BRCA mutation, if their test result were to come back negative, at that point in time we may not offer testing to the unaffected family members because that may be telling us that whatever is happening in terms of the cancer in this family may not be BRCA related. Conversely, if we’re able to test an affected patient first who tests positive for a mutation, we’ve then confirmed the etiology of the cancer in the family and we can then offer site-specific testing to the unaffected family members to determine if they’ve inherited that predisposition or not. If they have not inherited that, we’re able to revert their risk of breast and ovarian cancer typically back to that of the general population.

Barbara Johnston: If the test is positive, that doesn’t mean you have cancer or you’re going to have cancer. That means it’s genetic, and you have same gene as your sisters. That doesn’t mean you’re going to have cancer, but your risk is higher than in any other person.

Dr. Pablo Rodriguez: There are personal and familial characteristics that are considered indications to proceed with genetic testing: if somebody develops breast cancer at an early age – like in her 30’s or 40’s – if somebody develops bilateral breast cancer, if somebody develops both breast and ovarian cancer, and if there is a family history of male breast cancer. Those are some of the indications for genetic testing for a BRCA1 or BRCA2 mutation. Those are some of the indications for genetic testing for a BRCA1 or BRCA2 mutation. Also, if somebody has numerous family members with breast and/or ovarian cancer, that may also be an indication for testing for a genetic mutation in the BRCA1/BRCA2 genes. So family history is also very important.

TEXT: Prevention strategies:
TEXT: 1. Increased screening (mammogram and MRI)
       2. Chemoprevention (Tamoxifen)
       3. Preventative surgery

Jessica Kent: The options for breast cancer risk reduction include the option of prophylactic mastectomy, but there’s also the option of increasing surveillance through the use of mammography as well as breast MRI. In families that are BRCA positive, the women who have inherited this predisposition are recommended to start with annual mammography screening as well as annual breast MRI screening at the age of 25, which is significantly younger than maybe what would be normally recommended just based on that family history alone without that clarification of the hereditary predisposition. In terms of the increased risk ovarian cancer in these families, what we do recommend is that between the ages of 35 and 40, that they do consider having prophylactic oophorectomy, or removing both ovaries and fallopian tubes. The reason why this recommendation for surgery is much stronger than that for the bilateral mastectomy is because we really do not have screening for ovarian cancer that has been proven to consistently pick it up at its earliest most treatable stage.

Dr. Trevor Tejada-Berges: In our experience, women in general and Latina women in particular have proven to be very receptive to the concept of genetic counseling and genetic testing. And it’s important to emphasize that even in this population of women, where we focus on women because of their family history, that the majority of those women do not truly have a hereditary predisposition.
Barbara Johnston: I was talking to Dr. Tejada about how some women remove their ovaries, but he told me he doesn’t recommend it until 35 years of age or older. I’ve been thinking about it, and I probably will do it in next few years.

Dr. Trevor Tejada-Berges: At our clinic, among women who have a strong family history of breast cancer we found that approximately 25 percent of women referred for genetic counseling clinic were found to have a BRCA mutation. Among those women who were identified to have a mutation, the majority of those women chose maneuvers to actually reduce their level of risk. The majority of women who were found to have a hereditary risk for ovarian or fallopian tube cancer actually chose prophylactic surgery beyond the age of 35. The majority of women who were found to have a high risk of breast cancer either chose screening or prophylactic surgery commensurate with their level of risk.

Barbara Johnston: What I’m doing now is I’m getting the mammogram done once a year and MRI once a year, too. So I do it six months apart one from the other.

Dr. Trevor Tejada-Berges: Among women who are found to have a hereditary predisposition to either breast or ovarian cancer. Choosing how to manage that risk becomes a very personal decision and it generally involves a very frank conversation with your physician about what risks are acceptable to you as a woman.

I think this sometimes flies in the face of what we often think of in terms of how Latina women perceive their health care or perceive their risk. Much has been made of the concept of “fatalismo” or fatalism, a somewhat fatalistic perspective in face of diseases. We’re realizing that Latino women are very open to actually taking information and really making decisions based on that information in much more proactive manner than we might have thought of before.

Melanie Wasserman: One of my professors, Jeannie Ang, told me that she was working with a group that is considered hard to reach, and she asked them “why is it that your group is so hard to reach?” And they said to her ‘we’re not hard to reach, you’re hard to reach!’ And I think that’s true of medical providers in relation to the Latino community. The community doesn’t perceive that they’re hard to reach, they perceive that medical care is hard to reach.

TEXT: Barriers to BRCA genetic testing in Latinas

Jessica Kent: In one pilot study that was performed in California, they sought to set up these satellite cancer genetics clinics in the Latino community to determine what the interest level was and whether this group of women would take advantage of these services. And they did find that when they went out into the community and set up these satellite clinics, many of the women – over 80% of the women – did attend all of their scheduled genetics appointments. There was an overwhelming response showing that these women really are interested in taking advantage of preventative options if its in the optimal setting. By that we mean services available in their native language, having reading materials, educational materials, and also having trained providers who are experienced in identify high risk patients who are also Spanish speaking.

Isabel Pestana: I think of the challenges that a lot of [Latinas] face is that they don’t have health insurance. So yes we can educate them about the genetic testing, we can educate them about breast cancer, I think that’s great, now what can you do about it – I don’t have the money to go and do these tests. They don’t know who in the community can help them.
Melanie Wasserman: What I would ask other people in the community is, if you know an older women, a middle aged woman, who’s not married and/or doesn’t have kids, let her know that you value her and that for the community’s sake, that she should take care of herself -- because, we need you, and we love you.

Ericka Moore: When my mom got diagnosed in 2001, I had just started at NHPRI, and I wasn’t there not even 4 months and mommy got diagnosed with breast cancer. And it was nerve-wracking and scary. All I could think was “oh my god, my mom is going to die.” We were all involved, it was my father, my two brothers and me. We looked at all the different options, I always had my husband’s support in whatever I needed to do to go back home and help my mom. Because the doctors were explaining all these terms and the barrier of the language was...she couldn’t communicate with them. She literally had to call me and I was my mother’s advocate.

Barbara Johnston: It’s easy for me and for one of my sisters, yes she can talk about it. But my other sister doesn’t even want to talk about it. She is the one that had cancer. I would talk to them all I can just to get them to realize that it’s a problem in the family and we have to face it. We have to get tested and make sure we are ready for whatever comes.

Dr. Trevor Tejada-Berges: When we talk about hereditary predisposition, the concept of potential discrimination based on a hereditary predisposition certainly becomes very important in that conversation. It’s a big issue that’s brought up for all women, but specifically for Latina women, it does become a big issue. Fortunately, the Genetic Information Nondiscrimination Act, the so-called GINA Act, protects women against discrimination in terms of their hereditary predisposition, particularly as it relates to health insurance.

Isabel Pestana: We’re very religious or spiritual/faith-based but we also have a lot of sayings in our culture. One of the sayings goes something like this: Help yourself so God can help you. So I think it’s a reminder, and it’s so cultural, and I can understand and generalize it to South America, there’s this attitude, too, that you have to pray to your God but you also have to help yourself.

Dr. Trevor Tejada-Berges: I think that being a health care provider is an incredibly privileged position to be in. And none of us takes that lightly, particularly as it relates to Latina women – as a Latino man, I understand that there are a number of barriers that actually can come into play in that kind of a relationship. Not only understanding the language, but being able to understand the culture, having been raised in that culture, puts me in a position to be able to really help these women. And I think it’s an incredible opportunity and also allows us to debunk a lot of the myths that we have regarding how Latina women access healthcare. What we’re learning is really a lot of it depends on how that information is provided. If you really try to look at it from a more holistic perspective, we care about women not just looking at it from a disease perspective but looking at it from a cultural perspective, from their own religious beliefs, that we can actually help these women understand and manage their risks in ways that we might have felt they were able to care for.

Isabel Pestana: It’s a powerful role that the provider has to guide the well-being of the patient physically and emotionally but spiritually too as well. Figure out where they stand physically, where they stand in their mental health, where do they stand with their spiritual health, and take it from there.