

“It’s not that they are excluding anyone, but they think that it’s just the same for everyone”

Cancer does not discriminate

Seeking better support for marginalized and underrepresented women

In their words

Anyone diagnosed with cancer faces tremendous physical, emotional, and practical challenges. The same is true for women who aren’t white, middle class, well educated, or heterosexual, but research shows these women face additional burdens.

Over the past six years, researchers with the Ontario Breast Cancer Community Research Initiative (OBC CRI) have learned that women living on low incomes, those in rural areas, women of colour, immigrants, lesbians, young women, and seniors with breast cancer have specific supportive care needs that aren’t being met. While concerns vary, they can be summarized in two categories:

Access to Information Resources

It’s hard for many women to find information and resources that reflect their lives and address their needs.

Support and Communication

Service providers must be made aware of how and why needs and issues differ for diverse groups of women.

Access to Information Resources

Many research participants reported that available information simply “didn’t fit” their circumstances. They would especially like to see:

Representation of diverse groups in materials

The “model” patient most often depicted is white, healthy-looking, middle aged, physically active – and engaging in activities that require a middle class income. Occasionally, women of colour are represented, but they also tend to be lighter-skinned and appear affluent. Various participants noted they would be unlikely to pick up information that did not contain images to which they could relate.

Better explanation of specific issues

Many women weren’t made aware of treatment side effects like early menopause, and received little information about fertility and other physical effects. Many younger women noted there was little guidance about how to speak to children about cancer. There was also confusion around the safety and effectiveness of alternative therapies.

User-friendly information

Information is often not available in languages other than English, and is seldom tailored for different literacy levels.

The following are direct quotes from women experiencing gaps in information and support services.

“(Health providers) ignored my questions about sexuality and having children. They kept saying we will talk about that later on. Then menopause started and again I was left on my own to learn about what was going on.”

“The bottom line is that all the information that we have is geared to women over 50.”

“The information seemed to always focus on white women, to the extent that you would almost think that breast cancer is a white disease...”

“[I asked] the social worker... can you just tell me how to keep the shelter and food on my table ... because I just knew, I had to stay in that apartment, I couldn’t be homeless, and I had to feed my daughter and myself.”

“My doctor is really good... but I don’t know why, the first time I met her, she looked at me and she said, “how long have you been in Canada?”. I said, 5 years. And ... I don’t know what she meant, but the words that came out of her mouth were, “who let you in?”

“Like what if you got into a support group, came out [as a lesbian] and then had to deal with homophobia on top of everything else and then you’d be left with no place to go. So it’s almost better to go and hide, or not go at all, than deal with the stigma.”

The “model” patient most often depicted is white, healthy-looking, middle aged, physically active, and well off.

Cancer does not discriminate

Getting the right information flowing

The OBC CRI recommends these steps to improve information for all breast cancer patients:

Tailor information. Shape resources so they speak to the needs and realities of different groups, e.g., nutritional advice that reflects different diets and incomes, and education about cancer for children. Use diverse images in materials: e.g., women of different ages, ethnicities, abilities, and vocations, and women partnered with women.

Provide information in different forms. Various formats, such as videos, pamphlets, and one-on-one discussion, are needed at different times. They can be better adapted to different levels of understanding, and can be translated into many languages.

Give better direction. Guide patients to access further relevant services, providing contacts, numbers and encouragement.

Support and Communication

Social inequality and histories of discrimination against racial and cultural groups can limit the choices women make. Even the possibility or fear of encountering discrimination can dissuade someone from seeking help, while some women find that their needs are simply not addressed by mainstream services. Here are some examples:

Being “the only one”. Many women from marginalized groups said they felt isolated in support settings; often, a woman was the only person in a group from her particular community or age group. Some women said they would be unlikely to attend an event or group if it appeared to focus on the dominant patient.

Facing discrimination. Marginalized women sometimes reported that other women in support groups seemed uncomfortable around them. Other attendees or health professionals sometimes made blatantly offensive comments.

Services not fitting. Service providers often did not understand why some women’s needs were different, and were not able or willing to address them. Supportive devices or products, such as wigs, breast prostheses, and makeup, are designed mainly for white women.

Being unable to access services. Many women didn’t know what support was available, or did not find out early enough. Others had no access to services where they live, and some reported that services were too expensive for people on low incomes.

Little family support. Few programs exist for children, caregivers and partners – male or female. Family, caregivers, and friends are often uncertain about how to respond to and assist a cancer patient.

Building inclusive support

The OBC CRI has these recommendations for ensuring all breast cancer patients gain equal support:

Anti-discrimination education. Healthcare providers could benefit from attention to issues of inequality early in their training. Community support leaders could also learn about how and why the issues are different for various women, and how to better address them.

Specific support services for diverse groups.

Communities need help to develop support services that address their needs. Peer support programs could be offered for women from specific communities. Existing groups could develop and integrate elements in their services that address different needs, e.g., spiritual counseling from different traditions, and support services for lesbian partners, other caregivers, and children.

Built-in screening for supportive care needs.

The health system could establish systematic ways for care providers to inquire about social and support needs at diagnosis, and during treatment and follow-up.

A call to action

Breast cancer may not discriminate, but the healthcare system sometimes does. Working together, patients, healthcare workers, administrators, policy-makers, and support providers can develop solutions. To get started, cancer care coalitions and advocates need to share the information here. We must increase awareness about the need for better access to relevant information and a stronger support system for women across diverse communities.

About OBC CRI

The OBC CRI was created in 2001. Its goal is to understand the information and support experiences of marginalized women with breast cancer and then share these findings with the health system in the hopes that the needs of these women might be better addressed.

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