

# Women of Colour Living With Breast Cancer

## The Search for Support

JENNIFER NELSON AND FLORENCE AGYAPONG

*Cette recherche sur les femmes Noires qui vivent avec un cancer du sein a fait émerger. plusieurs thèmes dans les entrevues incluant la spiritualité, la culture, les contraintes à supporter ainsi que le racisme. Ce sont des thèmes reliés à l'héritage du colonialisme.*

*... black women need to know that there are other black women who are experiencing or have experienced this and support each other. (Doris)<sup>1</sup>*

A few decades ago, the subject of breast cancer was largely taboo, considered to be a private health matter between a woman and her doctor, and possibly within her family. Over the last 20 to 30 years, women's and patients' groups have organized widely, advocating for greater education and awareness among patients and the general public about the disease, as well as for more research funding to be directed specifically to this form of cancer. The feminist health movement has played a key role in this surge of interest and support, but mainstream groups and organizations have also rallied around the cause. It's a rare person who is not aware to some degree, today, of the plethora of fundraising and awareness events across North America. And it is a rare family that has not been touched in some way by breast cancer—whether directly or through friends who have been diagnosed. This era of increased awareness has seen great improvements in early diagnosis and survival rates, (albeit, neither as quickly nor extensively as most of us would like). Yet, this surge in awareness, education and support for those living with breast cancer has not been equally effective in all communities. Efforts at building the breast cancer movement have largely overlooked the views and experiences of women who are not middle class, white, heterosexual and middle aged.

This paper addresses the latter issue by presenting the results of a recent study with women of colour who have had a breast cancer diagnosis. We argue that cancer care is

a site that can replicate systems of domination, creating significant barriers to support for women of color living with breast cancer.

### Where We Come From

Late in 2003, a number of us came together to discuss the need to document the experiences of women of colour, who have long been underrepresented in breast cancer literature. We were: two leaders of a support group called The Olive Branch of Hope, for black breast cancer survivors in the Toronto area, an educator from a women's health centre, a nurse manager from a Toronto hospital and a researcher interested in issues of race within health care, based at the same hospital. We formed a project committee, wherein Florence Agyapong (the health educator) and Jennifer Nelson (the researcher) would conduct a study, while the others acted as advisors, consultants and liaisons with the community.

We came to this research from very different places, bringing some similar, and some very different perspectives and experiences. Florence is a black, Ghanaian biochemist, and a resident of Canada for the past four years. She currently works as an educator in communities of colour and teaches about key health issues, including breast cancer. Jennifer is a white, Canadian-born sociologist working with the Ontario Breast Cancer Community Research Initiative, which has a mandate to better understand the experiences and needs of marginalized women living with breast cancer.

We brought with us several key concerns from our different backgrounds. Jennifer wanted to know more about how systemic racism was reflected in, and constitutive of, the experiences of women of colour seeking support after a breast cancer diagnosis. Florence had studied illness experiences and coping mechanisms of women living with various health concerns in Africa, and wished to apply her skills in her current community. Our

advisory group brought their concerns about the lack of information available on women of colour and breast cancer in Canada, as well as their first-hand knowledge of the barriers minority patients face in finding support and information.

### Our Research Approach

We decided to focus our study on women's coping mechanisms and modes of support within the Toronto

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black community. Because two of our committee members had founded *The Olive Branch of Hope*, a support group for women of colour with breast cancer, it made sense to begin close to home, recruiting participants from the support group and its networks. We decided on a qualitative approach, using 15 in-depth interviews to capture women's stories of breast cancer from their own perspectives.

Our goal in doing the study was largely exploratory. We wanted to determine whether there were common themes in these patient narratives, and if

so, to elaborate their content. We also wanted to begin to document the stories of women of colour, as they are rarely present among breast cancer survivor narratives. We wanted to make these stories public (though anonymous) and available to newly-diagnosed women as they experience the isolation and fear that so many others describe. Importantly, we wanted to raise awareness among health care and supportive care professionals of the barriers some women face in accessing what are assumed to be inclusive services that are open to “anyone.” We knew this information would contribute to a broader knowledge base about women's access to health care when they are living on the margins of society due to systems of gender, race and class discrimination. We shared a desire to understand how these systems operate in women's everyday lives as they go about seeking support during a cancer diagnosis.

For the purposes of our study, we defined “supportive care” as encompassing any services aside from actual medical treatment that help women to cope with their cancers. In interviews, we gave examples such as individual counselling, group therapy, social work support, organized home services, and support groups. Discussion in the interviews fell heavily in the area of support groups as this was the form most commonly explored, due at least

in part to our particular sample.

Throughout the 15, face-to-face in-depth interviews, each woman was asked about the particular avenues of support she had explored, and about what she found helpful or harmful. We also asked each woman if she felt there were issues particular to women of colour when living with breast cancer, and if so, to expand on what these issues, needs or problems were.

In keeping with the community-based focus of the project, our advisory committee helped to review the interview guide, to discuss issues as they arose and to offer feedback on the data analysis and dissemination. We met most participants before the study began to explain the project and issues of confidentiality and to answer questions. Participants were given copies of their transcripts and invited to suggest changes or clarifications where needed. We have also presented the findings at fundraisers and health information events in the Toronto black community. In this paper, we have chosen to present the themes that emerged as the most pertinent and commonly-expressed concerns among the women.

### Our Participants

All the women interviewed, except one, had come to Canada from the Caribbean. All but one woman identified as “black” and many used “woman of colour” and “black” interchangeably to define their racial identity. One identified as West Indian and had been born in the United Kingdom. The average time living in Canada for all the women was thirty years, with a range of 23 to 42 years.

We interviewed women from a range of ages, the youngest being 37 and the eldest 71. Early on, two women expressed interest in the study who suffered from other forms of cancer. We interviewed them as well, feeling that despite our research mandate to focus on breast cancer, the issues we were exploring were applicable across cancer sites and, in effect, across various experiences of illness.

### Being the Only One

*Even from what I have seen in magazines, yes, there may be a black woman, but the ratio of minorities to Caucasian women is very small.... There is not a strong presence.... I have not honestly seen or heard any black women as advocates for the breast cancer [organizations]. (Doris)*

Many participants mentioned the lack of representation of women of colour in breast cancer magazine articles, informational literature, news reports, and among spokespeople. Several also talked about events that help women to deal with the appearance-related affects of cancer, noting that the wigs and make-up available suited only caucasian hair and skin tones. While this is not

surprising, the absence of visual and textual representation can have important consequences. For instance, one participant noted that another woman of colour had told her she used to think of cancer as a white person's disease.

*... One black lady said to me, "I thought only white people get breast cancer" because every information that were in the yellow book or research that were done was shown for white people.... (Candice)*

Similar beliefs have been found in other non-white communities where cancer information studies have been conducted (Jackson *et al.*; Guidry *et al.*). It is also important to note that women of colour in the U.S., while less likely to be diagnosed than white women, are more likely to die from breast cancer (Yood *et al.*; Smith, Phillips and Price; Shinagawa). Canadian statistics have not been collected for this population but other literature has suggested that lack of health information, awareness and the failure of physicians to recommend women of colour for early screening may contribute to disparities in survival rates (Thomas). When it comes to seeking support, our focus for this study, women described their reluctance to visit events, support groups or information sessions due to feelings of isolation and fear of racist exclusion, as in the following examples.

*[Women of colour might not come to a support group or look for counselling and other support services] ... maybe because of pride ... sometimes because of privacy, they don't want to give out any information ... and it is fear. I figured out that fear covers all the reasons why they don't want to do these things.... Fear that they might be hurt.... (Winnie)*

*It is obvious on a visual scale if a black woman walks into a room and they are the only black woman in the group. It is more than likely that they will be quiet.... If a black woman doesn't have a sense of security, that this support is a secure environment for them, they may not go. (Doris)*

### Spiritual Beliefs as Cornerstones of Exclusion

*[Why do you think some women of colour might not come to a support group?] One thought that actually crossed my mind.... I know that we are actually more religious, we believe in god and in faith ... that could be one of the reasons. (Alicia)*

Within our research sample, every participant spoke about the importance of Christian faith in the black community. In most cases, this form of spirituality was extremely important to the women themselves. Even in cases where participants were not open about their cancer diagnoses within their communities, they spoke about

having relied on their spiritual practice and church community for strength and comfort.

Many woman spoke about religion as a major area in which white support services did not meet their needs, as in the following two examples:

*From what I have heard [about other groups] you are not allowed to mention God. Now for us that is very difficult because God is the centre of our lives. (Grace)*

*You know we are a deeply spiritual people.... [In the hospital support group] I wasn't allowed to express myself the way I wanted to. I wanted to be able to say, "Look, you know, leaning on my religious background, talking about the Lord, talking about my faith, that is what helped me through." But I wasn't allowed to express that so I felt that being in a support group ... that were mainly all Caucasian was not going to be helpful or beneficial to me at all. (Rose)*

### Racialized Interactions in Context

While one participant had found a white support group in which she felt comfortable, in other scenarios where participants had visited white groups, racism also figured in their descriptions of the experience, even when difficult to read explicitly, as in the following example.

*[Race] wasn't mentioned, but that's always sort of very ambiguous. I mean, nobody comes openly saying "we don't want you here." It's just the way they treat you—you know they don't want you there.... Nobody is listening to anything you have to say, and if nobody's interested ... the normal reaction is "what I have to say is not important to them. (Rose)*

Another participant expressed explicit views about the state of racism and health care:

*One of the problems is that many people of colour find in hospitals and different places where they go to get treatment, they are sort of treated differently. They don't treat them the same as they treat Caucasians, the other groups. Although we are uniquely different in our make-up as a person we are the same and we like to be treated with respect, dignity, as other nationalities.... (Grace)*

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She went on to expand her analysis by making links to issues of national belonging and citizenship.

*... Sure we are a guest in your country but many of us have been here for a long time, we have contributed to the country's economy in many ways.... Therefore we will want our fair share of the pie in that we get respect, we get recognition and sure we would like monetary compensation too—some help when we cannot help ourselves after we put in our strength, our youth into the economy, then when we are sick we would like to get*

ness imposed by white colonial rule has depended on holding one's cards close, protecting oneself and one's family.

*[Why would you not want to share your experience with others?] ... It is a cultural thing ... and if we go back to slavery when our ancestors came to different countries as slaves, they had to be secretive ... not only from whoever are their enslavers, but also their own people because the enslavers will try to instigate the ones who are willing and who would tell tales... and will get them in trouble,*

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*something back.... So you know those are the things that concern us and sometimes make you a bit angry. And you wonder why can't we feel like we are a part of the society here. (Grace)*

In this explanation, the forces of marginalization that determine the support encounter are replicated at all levels of society—the health care institution, the economy, and the nation as a whole. Not all participants made such links from the micro to the macro, but many suggested that historical and cultural behaviours influenced their ability to seek support.

#### **Disclosure and Colonial Legacies**

*We don't—and this is all cultural—we don't share things openly, you don't talk about your body parts openly, and so many ... find it necessary to keep these things quiet. We find even in our group—they've been through it ... through surgery, and family members do not know about it. (Marilyn)*

*Some [black] people are ashamed of it and they don't want anyone to know they have it.... People look at cancer as a bad thing ... they don't like people to know ... me, I'm not shy of that. I tell anybody, but some people don't. (Beth)*

A number of women spoke about the difficulty of talking about a cancer diagnosis in their communities, feeling that the subject remained taboo due to cultural norms around keeping problems to oneself. This tendency toward secrecy was sometimes explained by making links to a historical legacy (as one person joked, “colonialism helped with that!”), in which surviving the divisive-

*and so it comes down from that generation where we are always taught ... not to be too open.... (Grace)*

Many of the women expressed a view that people of colour needed to be more open about their diagnoses so that others would feel less isolated, and with the hope that the community could become more openly accepting and supportive during illness experiences.

*... I find women of colour do not like to express their illnesses and when you know that someone of colour has experienced the same thing then I think [you] can relate to them. (Nadine)*

*... I find that women of colour we tend to hide a lot and keep things very quiet and I think we should expose it more and be more brave, go to the meetings and the sessions.... Caribbean people, we are very proud people and I find that we are fearful.... (Freida)*

The work of the support group, the Olive Branch of Hope, to which many of them belong, has itself been instrumental in raising awareness of the disease. In presentations at many church functions and fundraising events in the black community, the group has incorporated testimonials from women who are living with breast cancer. We have also presented the results of this study at several such events and have participated in their regular informational seminars on breast and other cancers in women.

*Honestly since we formed the group... I realized how many people of colour had been going through the same thing as I have been through... and I want to be able to help people because I didn't get the help.... (Winnie)*

## Considering Our Themes

Our central purpose in this short paper has been to allow the participants, through their quotes, to speak for themselves, to begin to make their voices accessible to a women's health audience. A striking feature of the highlighted themes is that they are inseparable, continually weaving together as different threads in the same stories. Woman after woman generously lent her time attempting to articulate for us the ways in which marginalized beliefs, culture, lack of representation, historical legacies and present-day racism all interlocked with one another, albeit in different ways and to different degrees, to constitute her experience of cancer and of finding support.

Even women who felt racism played a lesser role, or was not present, often went on to describe incidents in which, for instance, they simply had not felt comfortable in a white support group, or in which they felt "observed," as if they didn't belong, when they entered a breast cancer organization. While the sentiment that "cancer has no colour" was frequently expressed, it was often supplemented by descriptions of the need for exclusive spaces or the benefits and comforts of speaking among "your own people." Women who claimed not to care if a support group was particular to women of colour would often later state, for instance, that there were things they would not talk about if whites were present. For example:

*As black women we don't wanna be in a Caucasian group talking about our homes if there is anything at all negative. Not that there is, but if there is, we're not going to.... (Rose)*

Further, women who said that they were comfortable enough in mixed-group settings sometimes noted that they knew a lot of other women of colour who were not.

*A lot of people ... feel more comfortable talking about cancer in their own group.... You know it is important to a lot of people that it'd be just for women of colour ... but if a white person wants to walk in, I will be okay with that. (Kara)*

These seeming contradictions have presented something of an analytic dilemma. We were concerned with avoiding the projection of our own views about what constituted racism or an experience of discrimination. We also did not want to suggest that other women were simply unaware of racism or had somehow "missed" the meanings of their experiences. What we do suggest is that racism occurs in many forms along a continuum (Essed; Essed and Goldgerg). The experience of being looked at strangely upon entering a white organization, for instance, is not easily attributable to racism if one has not experienced this form of observation, but is very familiar to those who have.

In some situations there is not an explicit expression of discrimination, and discrimination may not always be intended. What is important to take from these examples is the sense that systems of domination operate in ways we don't always see or intend, as well as in ways we do. Their slippery definitions are part of the very difficulty of demonstrating to those on the upper end of power hierarchies that racism does, in fact, continue to permeate the lives of people of colour in western societies.

Our project team and our participants have not, of course, reacted to these findings with surprise or alarm. The exclusions and barriers women of colour face from white institutions and individuals are part of the continuum in which systemic racism is normalized. It has been crucial, however, to begin to create space for these women to tell their stories in their own words, to test our own assumptions, and to absorb the knowledge offered in their narratives. Although we have begun presenting the findings within the black community, what seems at least as urgent is our dissemination efforts among primarily white health care professionals, community groups and research audiences. There remains a need to interrogate cancer care as a site where systems of domination are, not surprisingly, replicated. While efforts have been made in health care settings over the last few years to better understand different cultures (see, for example, Chevannes; Gerrish, Husband and Mackenzie; Guidry, Mathews-Juarez and Copeland), the larger questions of power, of racism, remain elusive in much of this discourse (see Gunaratnam).

We hope that along with these inroads toward cross-cultural understanding come the larger waves of social change.

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health issues, including breast cancer. Florence holds a Master's degree in biochemistry from the Kwame Nkrumah University of Science and Technology, Ghana, and has done extensive research on illness experiences in African communities.

<sup>1</sup>Pseudonyms have been used in all quotations to protect the identity of participants.

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## HEATHER BRONDY

### Metaphor For How the West Was Won

hard on to hard on  
men move like mad ants  
reframing their broken home

like the sun  
their voices rise  
and become ghosts-chanting Cherokee  
warriors

who watch the dark hill  
against the dark sky  
where their wives make love  
to native politicians

there is  
a silhouette of feminine shadows on the  
skyline  
one chrysanthemum opening  
reshaping

and eyes that grow like a reflection in water  
swooning for the symmetry  
inside

and a hug on the hips

and the swaying.

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