The Arts

A white disease—the experience of cancer for black and ethnic minority women

For more on the **Leanne Pero Foundation** visit http://www.leannepero.com

On a Thursday evening in late March, I walk into the Copeland Gallery in Peckham's Bussey Building complex (London, UK). It's quiet outside, but inside is buzzing. Tickets for this event have sold out in advance and all 100 chairs in the main room are filled, with another 40 of us or so standing at the back. A DJ plays R&B and I am handed a bright pink cocktail that matches the balloons and neon cards lining the walls. On each card is a name, and next to it, a black and white portrait of a nude woman. All of these women have, or have had, cancer, and many are displaying their scars, but they also have something else in common: all are from black and ethnic minority (BME) backgrounds. Black Women Rising, the group behind, and in, the show began life as a cancer support network for women of colour, but tonight, in the first exhibition of its kind in the UK, the women involved are here in person to share their experiences and discuss the subtle ways in which cancer is perceived in their own communities, and also in cancer care services, as a white disease.

Every year, the National Cancer Experience Survey (NCES) collects feedback from around 70 000 people across the UK on their experiences as patients with cancer. The results reflect wide social inequalities, with women, non-white women, and the poor reporting lower scores, but even this reveals only part of the picture: just 50% of people from BME backgrounds participated in the 2017 survey, with the UK National Health Service citing "communication and language, taboos and stigma about cancer, concern about the security of their personal information, and cynicism about whether feedback will make a difference" as reasons for non-participation. But these factors do not just affect patient engagement in surveys, they drive to the heart of what shapes experiences in the first place, pointing to complex issues around trust in the medical establishment, assimilation, exclusion, and cultural differences in the way illness is understood and experienced.


Noam Friedman

This evening, the founder of Black Women Rising, Leanne Pero, is first to speak. For her, it all began when her treatment ended. After a double mastectomy and several rounds of chemotherapy for stage 3 breast cancer, Pero found herself in June, 2017, cancer free, but suffering from severe depression. Her clinical nurse specialist, she says, was unable to refer her to any appropriate post-treatment services, so she turned to the internet, blogging candidly about her experiences of fighting cancer. Before long, people started getting in touch, particularly BME women, encouraged to see someone they could relate to speaking openly about the disease. Some of these women had had similar experiences with post-treatment referral services, and very often felt they did not fit in at the mainstream support groups. But they also shared stories of isolation and exclusion within their own communities, in which cancer was sometimes thought of as a punishment, an embarrassment, or a curse, and western medical interventions regarded with suspicion.

"Some of the stories are horrific", says Pero on the phone the next week. "Things like being told, don't take the life-saving cancer drugs, such as chemo, because they're ungodly." She talks about a woman whose family refused to visit her because of fears of contagion. It is a lack of understanding of this cultural context, and a lack of diversity, says Pero, that makes mainstream cancer services ill-equipped to cater to BME patients. "Why are [the charities] not employing people that understand these people's cultural needs?"

In the absence of a forum where BME women could speak openly and connect with others, Pero, already a community organiser, decided to start a foundation. "We don't want any woman of colour", she says, addressing the audience, "to go through what we did again."

Black Women Rising had its first meeting in spring, 2018, under the auspices of the Leanne Pero Foundation, a charity set up to house various initiatives to support the BME cancer community. As each of the women takes to the stage, the therapeutic benefits of the group are clear. "When I meet with this particular group of ladies", says Rosemary Morgan, diagnosed with stage 3 breast cancer, "I can say anything and they just get it." Perhaps after this exhibition, a few more of us, inside and outside BME communities, will get it too.

Catherine Lucas