Reportage

Barriers to treatment for patients with breast cancer in Kenya

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The authors declare no competing interest.

For more on the **disproportionate burden of breast cancer in Africa** see *CA Cancer J Clin* 2006; **56:** 168–83 and *J Clin Oncol* 2009; **27:** 4515–21

For more on **cancer detected at advanced stage of disease** see **Series** *Lancet Oncol* 2013; **14:** e158–67

For **high mortality rates in Kenya** see *ecancermedicalscience* 2014; **8:** 426

For more on **cancer care disparity** see *J Clin Oncol* 2016; **34:** 6–13

For more on **factors affecting late presentation of breast cancer in Kenya** see *Archives of Medicine* 2015; **8:** 1–10

For more on **the issue of stigma for cancer** see **Essay Focus** *Lancet* 2006; **367:** 528–29

For more on **the use of alternative medicine for cancer** see *Ann Surg Oncol* 2011; **18:** 912–16

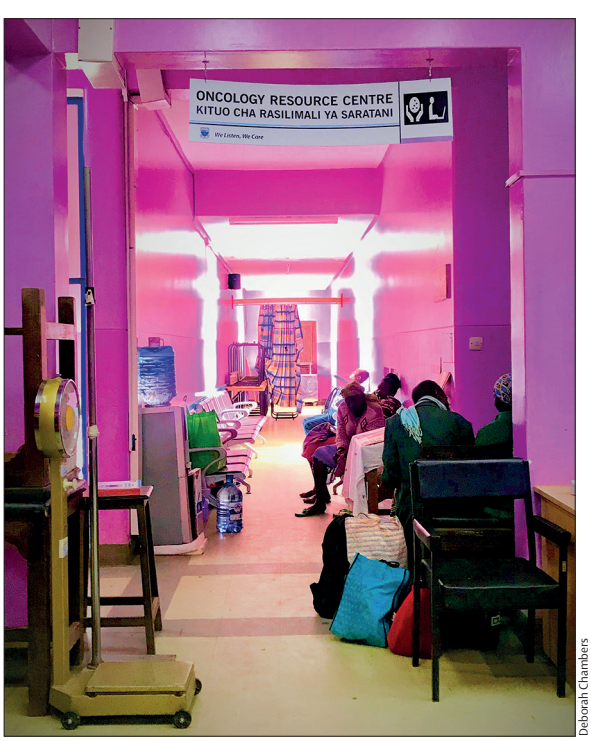
For more on **increasing incidences of breast cancer in Africa** see *J Clin Oncol* 2001; **19** (18 suppl)**:** 125–7 and Ministry of Health (2017), Kenya. National Cancer Control Strategy 2017–22

African women experience a disproportionate burden of breast cancer compared with women globally, and although the incidence of this disease in Africa is only a quarter of the incidence in North America, its related mortality in the two continents is similar. Mortality is high in Africa because patients often present to clinics at advanced stages of disease. Women from Kenya are a part of this population, contributing to high mortality found across the country. Moreover, there are gaps in the treatment and care of patients with breast cancer because many hospitals are not fully equipped to diagnose (ie, without equipment used to process and report on breast tissue biopsies), care, and treat the growing number of these patients.

In February, 2019, we did a study to understand important factors affecting the diagnosis and treatment of patients with breast cancer in Kenya. Our study took place at Kenyatta National Hospital (Nairobi, Kenya), the largest referral hospital in east Africa, where we interviewed 43 women with breast cancer who talked about their personal experiences of living with the disease. We found several factors that affected their care and treatment, such as inability to pay for treatment, long travel times for visiting specialist hospitals, feeling helplessness and hopelessness about their disease, having to live with cancer because of long waiting times, and inadequate access to educational information about the disease, test results, and treatment options. Additionally, we found that issues such as stigma, use of alternative medicine, and misdiagnoses associated with their illness that have not been widely reported previously also contribute to low treatment adherence and high mortality.

In our cohort of interviewees, many women discussed the stigma of having a cancer diagnosis. Although several diseases such as HIV/AIDS are stigmatised throughout sub-Saharan Africa, breast cancer also apparently made the list. According to one patient, "there is [a] stigma around breast cancer. People think they will die very fast." The stigma of having and living with breast cancer was a major concern to many participants, many of whom did not disclose their diagnoses to their families or to close relations. As one patient described, "I never disclosed my breast cancer diagnosis to any of my friends. [I tell a story] when I need to come to Kenyatta National Hospital for treatment for 3 weeks". Other women described how people started to treat them differently after being diagnosed with breast cancer: "People started avoiding me… People stare at me badly because of my wounds and they avoided me. It is not my fault that I am sick and look like this." One patient with breast cancer added, "Some people talk about me in a negative way, as if they don't understand [that the disease] is not acquired." One patient described how she only confided in people that she trusted, whereas another discussed how she dealt with others' reactions. We were also concerned to hear about patients' beliefs regarding the role of supernatural forces surrounding cancer, which causes fear that the disease is beyond their control and can contribute to decreased diagnosis and treatment. Throughout Africa, including Kenya, there is a belief in witchcraft that still holds a very strong place in African culture and ultimately influences health care and treatment. As some women described, there was a clear belief that cancer was a result of sorcery, although some women did explain that they knew it was probably not the real cause of the disease, despite believing in witchcraft. The effects of people believing that the disease was a result of bad *juju* was that other people would be fearful of the women who are jinxed with a breast cancer diagnosis. As one woman vividly described, "People are running away from me, even when I bump into them."

From a medical perspective, perhaps the most upsetting barrier to the care and treatment of patients with breast cancer was how frequently breast cancer



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was misdiagnosed and improper treatment was given. Misdiagnosis of the disease in rural Kenya results from inadequate access to health care, as well as no diagnostic technology and treatment options. As one patient we interviewed recalls, "I went to St Mary [hospital] in 2015 [to review my lump]. [The doctors] told me it was breast milk that had accumulated in my breast, so they asked me to return home and wait, and then it would go away. After 1 year, that lump started growing. I went back and [they] told me it was not an emergency. I gave up and went back." Other physicians advised women who had lumps in their breast that they were related to the birth control they were using, and that if they were experiencing side-effects they should change birth control. Some patients also described that even when breast cancer was correctly diagnosed, their prognosis was incorrect. "The doctor told me I was going to die and needed to call my children", one patient recounts after visiting her local rural hospital near Kisii. "He told me I will not recover. I was told I was at stage 4. I decided to wait for my death because the doctor told me there will not be any cure. [But after being diagnosed at Kenyatta National Hospital, I found out] I was at stage 1".

Unsurprisingly, we learned that many patients with breast cancer use alternative medicine. Many people in rural communities in Kenya self-medicate because of poor access to treatment and high costs of standardised health-care services, as well as increased availability of alternative medicine in rural areas. Some of these treatments were not harmful to health, such as using warm water to wash the breast, but others seemed to have more harmful consequences. "I [applied] *miti shamba* [a traditional herbal medicine]. I would wash my breast, wipe it clean, then apply [crushed] ashes to the wound, which made it worse because it got more infected. I did this for 4 years [two times a day]," one patient described. Other women used warm water, peroxide, and lemon to prevent their wounds from smelling, which, in one case, resulted in skin peeling. Although various patients reported that family members promoted the use of alternative medicine, other women described that many self-made doctors promoted the use of herbal tea.

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Living with cancer is difficult everywhere in the world, but these personal stories highlight additional obstacles that women in Kenya have to face. Almost every patient talked about the cost, travel times, inaccessibility of care, and negative symptom interpretation associated with having a cancer diagnosis—all aspects that have been well researched and understood before. Despite these factors, however, there were also additional barriers such as stigma, witchcraft, alternative medicine use, and the experience of a misdiagnosis that affected proper treatment. Stigma, for example, discourages people to actively seek care, whereas alternative medicine is used because people cannot afford treatment, which can contribute to disease progression and self-harm. Additionally, a culture of witchcraft can delay treatment because of the belief that sorcery causes cancer and that no treatment exists for the disease, or there is a belief that a spell must be reversed before modern treatment can be applied. All these factors affect seeking, continuation, or completion of treatment for breast cancer. After discussing these findings with colleagues at the UN, WHO, Kenya Red Cross, and African Medical and Research Foundation (AMREF) Health Africa, it became even more apparent that the information in these stories has not been previously identified, but was uninanimously regarded as very alarming.

Cancer incidence in Kenya is steadily increasing. This trend means that care for patients with cancer in Kenya, which is already inadequate because of poor access to diagnostics and treatment, will continue to be more widespread and worsen if political, economic, and social changes are not made. The capacity to provide comprehensive care is limited by cost, inadequate infrastructure and workforce, cultural barriers, and inconclusive or incomplete data. We believe that education could ameliorate some of these outcomes, as both the public and physicians would be better able to choose the type of treatment and care needed and stop harmful practices that delay the improvement of health outcomes for those most in need.

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