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Characteristics and presentation of patients with breast cancer in Rwanda

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Abstract

BACKGROUND: Breast cancer is prevalent globally, yet outcomes are worse in low-income countries than in high-income countries. Anecdotally, women with advanced breast cancer in Rwanda are increasingly seeking care, yet little is known about their presentation and demographics.

METHODS: We retrospectively identified patients with breast tumors—from operating theater logs, admission registries, and pathology reports—who were treated at 3 referral hospitals between January 2007 and May 2011. Sociodemographic and clinical data were extracted from inpatient charts.

RESULTS: One hundred forty-five patients received care during this period. The average age was 48.5 years. Eighty-five percent presented with more than 12 weeks’ delay after an abnormality was noted. Forty-eight percent underwent mastectomy, 20% lumpectomy, and 3% mastectomy and chemotherapy. Data on stage were limited and histopathologic data were unavailable.

CONCLUSIONS: This study is the first to characterize Rwandan patients with breast cancer. Our results highlight the need for registries to capture stage, pathologic features, and survival, as well as the need for research on causes of delayed presentation in Rwanda.

Breast cancer is the most common cancer in women, with approximately 1.4 million new cases diagnosed annually worldwide.1 There is great disparity in outcomes across regions: there are higher case fatality rates in low-income countries than in wealthier countries.2 For example, the age-standardized incidence rate of breast cancer in East Africa is 19.3 cases per 100,000 women per year and mortality is 11.4 deaths per 100,000 per year. By comparison, the incidence rate of breast cancer in the United States is 76.0 per 100,000 women and mortality is relatively low at 14.7 per 100,000 per year.1 Therefore, the estimated case fatality rate in East Africa is overwhelmingly higher at 59% compared with 19% in the United States. Lack of comprehensive cancer care in low-income countries is surely the major contributor to this global inequality.2 In addition, differences in age, incidence, stage at presentation, and tumor pathologic characteristics between white and black women with breast cancer in South Africa and the United States suggest biologic and socioeconomic factors may also have important influences on the advanced presentation and poor outcomes of African women with breast cancer.3-5

In Rwanda, a small population-dense country of 10.7 million individuals in East Africa,6 breast cancer is
currently poorly characterized. The Rwandan breast cancer incidence rate of 12.3 per 100,000 women is extrapolated by pooling data from other countries in the region. There are no available data on breast cancer case fatality rates in Rwanda. Human resources available to treat patients with breast cancer are extremely limited, with 2 clinical pathologists, 15 general surgeons, and no oncologists or surgical oncologists in the country. Infrastructure is limited as well, eg, radiation therapy is available only in neighboring countries. However, because morbidity and mortality from infectious diseases and maternal mortality are decreasing in Rwanda, the Ministry of Health is now targeting cancer care as a priority among noncommunicable diseases. Partnerships with academic medical centers, such as Brigham and Women’s Hospital and the Dana Farber Cancer Institute, nongovernmental organizations such as Partners In Health, and others, are evolving to include in-country clinical services, remote consultations, and training of Rwandan care providers in comprehensive cancer care. Rwanda’s first cancer center of excellence opened in July 2012 at Butaro District Hospital through a collaborative partnership with Brigham and Women’s Hospital, Dana Farber Cancer Institute, and Partners in Health.

Surgical consultations for breast cancer in Rwanda frequently involve presentations of late-stage disease, necessitating radical surgery for treatment or palliation. Patients may initially present to a traditional healer or health center in a delayed fashion after noting a breast abnormality or experiencing other symptoms. After a trial of local medications or observation, the patient may then be referred to a district hospital (rural hospital, typically 100 to 200 beds); however, unless the local general practitioner or a visiting surgeon is able to perform the required procedure, the patient is then sent to 1 of the 3 central referral hospitals: the Butare University Teaching Hospital (420 beds), Kigali University Teaching Hospital (513 beds), or King Faisal Hospital (130 beds). Many variables, including those related to the patient, provider, and health care system, can contribute to the delay in definitive treatment in these patients. To better understand reasons for these delays and methods to combat them, we first sought to characterize the demographic and clinical characteristics of women presenting for evaluation and treatment of breast cancer in Rwanda.

Methods

Institutional Review Board approval was obtained from the Ethics Committee of the Kigali University Teaching Hospital (which is a centralized review board for the 3 central referral hospitals in Rwanda); because of the deidentified nature of the data the study was exempted for review by the Harvard Medical School Institutional Review Board. Patients with breast cancer were identified through retrospective review of operating theater log entries, inpatient admission and treatment registries, and pathologic reports at the 3 referral hospitals in Rwanda from January 2007 to May 2011. Patients meeting the inclusion and exclusion criteria were entered into an electronic database. Inclusion criteria included having undergone a breast lumpectomy, resection, or mastectomy, or having a diagnosis of a breast cancer, mass, nodule, or tumor. Patients with available negative findings on biopsy were excluded. When possible, clinical data were retrieved from archived patient charts.

Data was analyzed for descriptive statistics, including frequencies, means, and standard deviation of patient age, sex, occupation, parity, geographic origin, procedural intervention, and delay to presentation.

Results

A total of 145 patients meeting the inclusion and exclusion criteria were identified. Forty percent of these patients had received clinical care at King Faisal Hospital, 29% at Kigali University Teaching Hospital, 23% at Butare University Teaching Hospital, and 8% at various district hospitals. Almost all were female patients (97%). Mean age was 48.5 ± 14 years (range, 15 to 89 years). Of 59 patients with residence data, 95% were from rural areas. Patients from all 5 provinces in Rwanda (Fig. 1) were represented; however, only 2% of the patients came from the northern province (which has 21% of the overall population) (Table 1). All patients who listed professions were farmers (n = 25). Parity was recorded in 20 patients, and on average patients had had 6 ± 2.8 live births.

The majority of the patients with recorded interventions for diagnosis or treatment, or both, (n = 82) underwent surgery. Forty-eight percent underwent mastectomy, 20% lumpectomy, and 3% mastectomy and chemotherapy. Another 28% underwent chemotherapy only and 1% underwent radiotherapy. Very few charts had TNM staging data (n = 7). Of these, 57% were stage III or greater.

In 33 charts, a documented patient history described the delay from the patient’s or health care worker’s detection of an abnormality to the intervention of record. Eighty-five percent of these patients had a delay of greater than 12 weeks, with 41% having a delay greater than 1 year (median, 48 weeks of delay). There were no statistical differences in age (P = .17) or rate of receiving surgery (P = .41) between patients with delay in presenting of less than 12 weeks and patients with delay greater than 12 weeks.

Comments

The demographic and clinical characteristics of Rwandan women with breast cancer have not previously been described. Based on the limited available data presented here, Rwandan patients with breast cancer are young (48 vs 61 years median age in the United States), present with advanced-stage disease, and have notable delays in receiving clinical care. There may be regional disparity in the
ability to access care in Rwanda, particularly for patients from the remote northern province. Although patients with breast cancer can receive surgery and chemotherapy at referral hospitals, the total number of identified cases (145 over the 3.5-year study period) was nearly 20-fold fewer than would be expected (estimated at 2,460 total or 702 new cases annually based on an incidence of 12.3 cases per 100,000 women and a country population of 5 million women). Lastly, based on the reviewed treatment records, chemotherapy is available at 1 institution (King Faisal Hospital, accounting for the larger proportion of patients receiving treatment there) and multimodality breast cancer care is not being provided in Rwanda at present.

These findings give us direction for addressing the gaps in providing comprehensive breast cancer care in Rwanda. Just as breast cancer outcomes improved in the United States after the introduction of early diagnosis and curative surgical treatment but before the advent of expensive health care technologies such as mammograms, it is feasible for breast cancer in the developing world to become a survivable disease. As surgeons working in low-income countries, we are supportive of the call to action by the global health community to expand cancer care and control in these settings. Surgery has an essential role in a multidisciplinary approach to the continuum of cancer care that includes prevention, early diagnosis, treatment, and palliation. As such, development of surgical services must be integrated into the planning for cancer centers. As an initial priority, funding from local governments and donors is needed to build these cancer care programs. Partnerships
with global and local surgical organizations and ministries of health are required to build physical infrastructure and supply chains to eliminate the implementation bottleneck for surgery. Training of local surgical providers (both surgeons and general practitioners) in appropriate biopsy and resection techniques should then follow.

To address the gaps in information about cancer pathologic characteristics, stage, and survival, national cancer registries will be required. In Rwanda, efforts are under way to build a national cancer registry as part of the National Cancer Action Plan. Again, surgeons play a critical role in obtaining this information. With appropriate registry information, clinical care is enhanced and research into the barriers to accessing care, the most effective treatment programs, and predictors of outcomes is made possible.

The most striking finding of the data analysis was that 85% of patients had longer than a 12-week delay from a patient- or provider-noted abnormality to a documented clinical consultation, procedure, or treatment. Delays of 12 weeks or more are associated with decreased survival in patients with breast cancer, making addressing the causes of delay critical. Similar to our patients, patients with breast cancer studied in Ghana had long delays in seeking treatment. Reasons for delay in the presentation of patients with breast cancer in Ghana include fear of mastectomy, financial barriers, and use of traditional treatments. More research is required to understand demographic variables associated with delay and identifying when in the clinical care pathway the delay is occurring in Rwanda: at the time the patient notes an abnormality, when she presents to a provider, is referred by a provider, receives a diagnosis, receives treatment, or at more than 1 of these points. Multifaceted strategies that include patient, community health worker, and physician education will be needed to improve detection rates, and the health care system will require significant strengthening to provide the multimodality therapy needed to cure breast cancer.

The cultural aspects of health care–seeking behavior are likely extremely important to the rate of breast cancer detection in Rwanda. The proportion of women with breast masses seeking traditional treatment is unknown but is likely high. However, traditional healers need not be seen as an obstacle to access to early evaluation by allopathic providers. Likely the best approach to strengthening the referral system for breast masses in our setting is a community-based sensitization program. This method has been successful in promoting awareness, decreasing stigma, and increasing case finding in child malnutrition and human immunodeficiency virus/acquired immunodeficiency syndrome. Thus, we recommend using the existing human resources for health infrastructure, including community health workers at the district level, nurses at the health center level, radio announcements, and the establishment of screening programs to drive a breast cancer sensitization campaign in Rwanda.

There are limitations to this study, most notably the reliance on retrospective data, some of which was incomplete, and the use of multiple data sources from multiple sites. This lack of sufficient well-organized data on breast cancer again highlights the need for a formal national cancer registry in Rwanda to track clinical volume and outcomes. An additional limitation is that district hospitals, the first entry point of care in the Rwandan medical system, were not included in our registry review. However, in our experience it is rare for a patient to receive either diagnosis or definitive cancer treatment in the district hospital because of the lack of trained surgical and pathology personnel.

**Conclusions**

The lack of equity in cancer care globally is striking. Although women with breast cancer from high-income countries have steadily improving outcomes, our observations and those of others suggest that women from low-income countries are not receiving timely diagnosis and treatment, representing a missed opportunity for cure. Surgical services are integral to surmounting the access divide in breast cancer care, and as such surgery is a fundamental human right that should be guaranteed irrespective of wealth or circumstance.

**References**