

Grand Anse Women's Special Health Program 1990-2017

Background

Women's health in low and middle income countries (LMICs) has focused solely on their role as mothers: pregnancy, family planning, child care and infectious disease affecting their reproductive health such as malaria and HIV. Non-communicable diseases such as breast cancer have not been a priority.

Haitian women are the heart of the family as well as the social and economic head of many households. The loss of a mother in Haiti is devastating to the family. When a mother dies for any reason, children are at greater risk of malnutrition and death to age 12 (Anderson et al., 2007). Breast cancer is the most common cancer and leading cause of cancer-related deaths for women worldwide. (Porter 2009) Estimates of the annual breast cancer incidence in Haiti are 4.4/100,000 and mortality 2/100,000 (Sharma et al 2013), compared to 67.8 in high income countries and 23.8 LMIC globally (Porter, 2009). This clearly shows that there is major breast cancer under-reporting in Haiti, as well as a high mortality rate (45%) for those cases that are identified (Sharma et al 2013). One study in Port au Prince found that 79% of women presented with advanced breast cancer and 28% had metastatic disease (DeGennaro et al 2015). National standards for breast cancer care are not readily available. Standards of care have been outlined for LMICs (Harford, 2011), but without funding for implementation. The actual prevalence is unknown and epidemiological surveillance does not systematically include breast cancer (World Health Organization, 2014). While surgical intervention is available in cities like Port-au-Prince, women living in rural areas like the Grand Anse have limited access to these options. Therefore, breast health services must begin with families in rural villages, local health workers, clinic nurses, diagnostic personnel, medical doctors, surgeons, epidemiologists and fellow survivors.

History of Breast Cancer Initiatives in Rural Grand Anse

The Grand Anse has never had systematic breast-health programs, either through the Government or voluntary health organizations, according to the Grand Anse Health Director (D. Montinor, personal communication, 2014). Despite the need for services in Jèremie and the surrounding Grand Anse Province (population 400-500,000) (<http://www.geohive.com/cntry/haiti.aspx>), breast health has only been addressed through sporadic education of nurses, intermittent sessions for clinical breast examination, and rare biopsies completed by visiting doctors. Early efforts in breast biopsy and pathology assessment began in 1990 through an affiliation with Hartford Hospital Connecticut volunteers.

The challenges are many:

- Families cannot afford biopsies, surgical and medicine
- Lack of adequate number of clinicians trained
- Breast pain though a common reality, is not completely understood and educational messages need improvement
- No post-operative physical therapy available to prevent lymphedema
- Lack of affordable tamoxifen (part of the WHO Essential Medicines list)

Mathilde's Story

Mathilde held her arms close to her chest as if to hide what lay beneath, but the smell of infected flesh unmistakable. There was nothing more to be done at the hospital and she was being discharged. During this process, she mentioned that she had no money for the trip home to her village and had not eaten that day: the very little money she had left was needed for food. This situation was explained to Dan Scoppetta, a Connecticut doctor touring the hospital after a week-long surgical trip to another part rural Haiti. With tears in his eyes, he offered her some money for the trip home. Scoppetta could not get her out of his mind: how could it be that this woman had received no prior care? But, advanced medical care in the capital city of Port-au-Prince was impossible, as Mathilde had no family there. She had hid her "condition" until it was too late. Ultimately, the social and financial cost of Mathilde's care was too great.

Scoppetta was haunted by Mathilde, and though she could not be saved, she was not forgotten. She was soon brought back from her village to the St. Antoine, the Haitian governmental hospital in Jeremie. A nurse gently cleaned the wound as you can see in the image below.



From St. Antoine, she was brought to the hospice of the Missionaries of Charity in town. She was fed, her wound dressed and she was nursed with loving care. Her husband and children made the trip to see her over the next two weeks. The smell was gone, and her pain under control because of a small gift of medicine, one that many outside of Haiti take for granted. Shortly after, she died. She was 52 years old.

- Lack of anesthesiology and surgical support and equipment to open a second surgical suite
- Inadequate support for the one general surgeon in Jeremie
- Palliative care is not readily available
- The national cancer registry is not consistently utilized
- Epidemiology of breast cancer in rural Haiti is unknown

There has been progress to establish a women's health program affiliated with the Health Department of the Grand Anse and St. Antoine Hospital, through the University of Connecticut Department of Community Medicine, the Avera Health System Haiti Mission (Sioux Falls, SD) and volunteer nurse practitioners. In 2011, Gebeau Methodist Clinic and the hospital welcomed a volunteer medical and nursing team to assist with screening and diagnostics. Clinic and field staff attended seminars about cancer and clinical breast examination (CBE). Breast models were obtained for education of nurses. In 2012, a Haitian American nurse, cancer survivor and President of the Marie Louise Cancer Foundation in Boyton Beach Florida, provided a series of seminars for health professionals and women. Call-in talk shows were held with three local stations. A portion of clinic nurses were trained, performed CBE and referred women for advanced diagnostic care and counseling. From 2012-2015 week-long collaborative breast health clinics were conducted. However, many these efforts were short-term and referral the only option.

Current Initiatives and Proposed Interventions

A comprehensive program for women and their family's needs to be established in the Grand Anse. Steps towards this goal are already being taken. In 2015, the US-based National Consortium of Breast Centers (NCBC) welcomed the public health anthropologist and nurse, Bette Gebrian, RN, MPH, PhD as an international delegate to their annual meeting. Relationships were forged and areas of collaboration identified. The Avera sonography and biopsy team continued their commitment and encouraged others to join in. Limited amounts of the medicine tamoxifen were secured for women in greatest need. Community-level canvassing continued and local health personnel began plan for the future.

In 2016, Jean Robert Dougè, a Haitian MD trained in Cuba and practicing in Jèremie, was granted an even more extensive scholarship by the NCBC. He spent a month in Montreal at a breast center to learn all aspects of the cycle of care – from counseling to post-surgical treatment with interdisciplinary teams. He attended the National Convention and was certified in clinical breast examination. He also addressed the several hundred participants regarding the need for a Women's Health Program in Haiti. He outlined the requisite needs to make the program a reality; providing education, training, training models, leader seminars, clinical screening, diagnosis and treatment (including surgery), survivor support, and mastectomy supplies. In 2016, a sonogram machine was donated by Mary Lanning Healthcare (Hastings, NE). Surgical and anesthesiology equipment and supplies have been donated by Bristol Hospital and affiliates (CT)

The program continues to develop. The Grand Anse Health Department, which governs St. Antoine Hospital, has assured support where possible. Local doctors and nurses are willing to be trained in screening and referral. The general surgeon in Jeremie town has collaborated with the voluntary surgical team led by Dr. Dan Scoppetta from Connecticut. Surgery was conducted a month after hurricane Matthew devastated this part of Haiti in 2016. Collaboration is still needed in the area of surgical supplies and upgrading equipment. Discussions are underway with the Anesthesiology Residency program to support these efforts as well as provide continuing education for the local nurse anesthetists. A public health anthropologist and sociologist are planning a focused ethnographic survey to understand the broad range of factors and beliefs affecting breast cancer screening and treatment. A local businessman donated a building for education, screening and diagnostics in 2017.

The most challenging part of assuring a sustainable program is establishing shared goals between the Haitian health services and the commitment of US partners and collaborators. This important foundation has been laid. We now need the resources to create a sustainable and effective program. Inclusion in the National Cancer Registry need to be improved and epidemiological surveillance strengthened. All of these activities combined will ensure that women in this region have access to education, early screening and surgical intervention for breast cancer, making this a curable disease. We have the capacity to make a difference.

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