

Grand Anse Women's Health Program

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 (Stage III or IV), and 28% had metastatic disease (DeGennaro et al., 2015). Haiti has no national guidelines or standards for breast cancer care. 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 volunteers.

The challenges are many:

- Families cannot afford biopsies, surgical, and medicine expenses in Port-au-Prince;
- Mammography services are lacking;
- Young women do not understand menstrual or fibrocystic breast pain vs. breast cancer symptoms;
- Educational messages need improvement;

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.

- Post-operative physical therapy to prevent lymphedema is unavailable;
- Tamoxifen (part of the WHO Essential Medicines list) is affordable, but scarce;
- St. Antoine Hospital needs anesthesiology and surgical support and equipment to open a second surgical suite;
- Shipping into Haiti is difficult and existing sources of supplies are expensive;
- Palliative care is not readily available.

Despite these challenges, small, promising steps have been taken to establish a women's health program affiliated with the Department of the Grand Anse and St. Antoine Hospital, through the University of Connecticut Department of Community Medicine, The Sisters of the Third Order of St. Francis (Springfield, IL), 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 donated by Johns Hopkins University School of Nursing. 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. Radio talk shows about breast health were taped and re-broadcast and people were encouraged to call with questions. Clinic nurses were trained, performed CBE and referred women for advanced diagnostic care and counseling. In 2012 and 2013, week-long collaborative breast health clinics were conducted. However, many these efforts were short-term and must be expanded to provide continuous, sustainable care to the women of the Grand Anse.

Current Initiatives and Proposed Interventions

A comprehensive program for women and their families needs to be built and sustained based at St. Antoine Hospital. 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 from Haiti to their annual meeting. Relationships were forged and areas of collaboration identified. The Avera sonography and biopsy team continued their commitment. Limited amounts of the medicine tamoxifen were secured for women in greatest need. Community-level canvassing continued and local health personnel began to track screening results, treatment and outcomes.

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 clinic 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 in Hastings, NE. Surgical and anesthesiology equipment and supplies have been donated by Bristol Hospital and affiliates in CT.

The program continues to develop. The Grand Anse Health Department, which governs St. Antoine Hospital, has assured epidemiological surveillance. Local doctors and nurses are willing to be trained in screening and referral, the surgical team at the St. Antoine Hospital is willing to learn and conduct surgical interventions, and US providers, including a team lead by Dr. Dan Scopetta, are willing to work in partnership with the Haitian staff to expand their training in sonography, surgical techniques. They are also willing to acquire more anesthesia equipment and supplies and provide nurse-to-nurse continuing education. A public health anthropologist and sociologist are willing to complete a focused ethnographic survey to understand the broad range of factors and beliefs affecting breast cancer screening and treatment.

The most challenging part of initiating and sustaining a program like this is establishing shared goals between the Haitian health services and the commitment of US partners. This important foundation has been established. We now need the resources to create a sustainable and effective program for Women's Health in the Grand Anse Health Department of Haiti. In particular, funding is needed for resources such as surgical and medical equipment, medications for breast cancer management, like Tamoxifen, and nursing education. These resources will ensure that women in the Grand Anse receive screening and early treatment for breast cancer, making this a curable disease for rural women like Mathilde.

References

- Anderson BO, Yip CH, Smith RA, Shyyan R, Sener SF, Eniu A, et al. Guideline implementation for breast healthcare in low income and middle income countries. *Cancer* 2008; 113(58):2221-2243.
- Anderson FWJ, Morton SU, Naik S, Gebrian B. Maternal Mortality and the Consequences of Infant and Child Survival in Rural Haiti. *Maternal and Child Health Journal* (2007) 11:395-401.
- DeGennaro, V Jr, Patberg, E, Libby, R, Gabriel, D, Auguste, JR, Suprien, VC, Al-Quran, S, Kasher, M, Heldermon, C, Daily, K, and Hurley, J. Epidemiologic, clinical, and histopathologic features of breast cancer in Haiti. Submitted February 13, 2015 to *Journal of Global Oncology*.
- Ferlay J, Shin H, Bray F, Forman D, Mathers C, Parkin D. Cancer incidence and mortality worldwide: IARC CancerBase No. 10. Lyon, France: International Agency for Research on Cancer; 2010
- Haiti. World Health Organization – cancer country profiles, 2014. (No reliable statistics on incidence)
- Harford, Joe B. Breast-cancer early detection in low-income and middle-income countries: do what you can versus one size fits all. *Lancet Oncol.* 2011 Mar;12(3):306-12. doi: 10.1016/S1470-2045(10)70273-4
- <http://www.cancer.org/aboutus/globalhealth>
- Jeungok Choi. Development and pilot test of pictograph-enhanced breast health-care instructions for community-residing immigrant women. *International Journal of Nursing Practice* 2012; 18: 373–378
- John RM, Ross H. The global economic cost of cancer: American Cancer Society & LIVESTRONG; 2010
- Marx, Andrew. Cervical and breast cancer: progress, challenges, priorities, and prospects since ICPD. ICPD Beyond 2014. Expert Meeting on Women’s Health-rights, empowerment and social determinants. Background Paper #6. Sept 30-2 Oct. Mexico.
- Porter, Peggy L. "Global Trends in Breast Cancer Incidence and Mortality." *Salud Pública Méx Salud Pública De México* 51 (2009). Web.
- Reeler, Anne. Women’s cancers in developing countries: from research to an integrated health systems approach. *Asian Pacific Journal of Cancer Prevention*, Vol 10, 2009. 519-26.
- Sankaranarayanan R, Ramadas K, Thara S et al. (2011). Clinical breast examination: preliminary results from a randomized controlled trial in India. *Journal of the National Cancer Institute*, 103:1476-1480.
- Sharma, Ketan, Ainhoa Costas, Ruth Damuse, Jean Hamiltong-Pierre, Jordan Pyda, Cecilia T. Ong, Lawrence N. Shulman, and John G. Meara. "The Haiti Breast Cancer Initiative: Initial Findings and Analysis of Barriers-to-Care Delaying Patient Presentation." *Journal of Oncology* 2013 (2013): 1-6. Web.
- Shulman LN, Willett W, Sievers A, Knaul FM. Breast cancer in developing countries: opportunities for improved survival. *Journal of Oncology* 2010;2010:1-6.
- The Breast Health Global Initiative. Breast health global initiative offers unprecedented tools for developing nations. News release April 1, 2011. www.bhgi.info
- World Health Organization and International Agency for Research on Cancer. World cancer report 2008. Lyon, France; 2008
- World Health Organization. Global status report on noncommunicable diseases 2010: World Health Organization; 2011.
- Yip, Cheng-Har. Guideline implementation for breast healthcare in low-and middle-income countries: early detection resource allocation. 2008. American Cancer Society. Supplement to *Cancer*. Published online 3 October 2008 in Wiley InterScience (www.interscience.wiley.com).