Current Breast Cancer Reports (2019) 11:152–157
https://doi.org/10.1007/s12609-019-00321-7

GLOBAL BREAST CANCER (AB CHAGPAR, SECTION EDITOR)

Promoting Breast Cancer Awareness and Clinical Breast Examination in the LMIC: Experiences from Tajikistan, Pakistan and Kenya

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Published online: 25 July 2019

Abstract

Purpose of Review Breast cancer is the most common cancer and a leading cause of cancer death among women living in low- and middle-income countries (LMIC) despite declining mortality in high-income countries. The rising morbidity and mortality from breast cancer is fueled by a number of factors including late presentation, poor access to medical care, and less than optimal diagnostic and therapeutic capabilities. Reducing the breast cancer burden in LMICs will require improving early detection and overcoming barriers to accessing the health system as well as making diagnosis and treatment more affordable. While North American guidelines advocate for mammography as the most effective screening approach, most developing countries do not have ready access to the technology, nor the trained workforce needed to perform and interpret mammograms.

Recent Findings In this paper, we present perspectives from Tajikistan, Kenya, and Pakistan and report on efforts to address the burden of breast cancer through screening and early detection programs. Given the significant proportion of women diagnosed with breast cancer in LMICs who present pre-menopausally and with higher grade tumors, widespread screening mammography may not be the most cost-effective approach.

Summary Based on the current evidence and our experience in LMICs, we suggest an approach which prioritizes population-wide education and self and clinical breast exams as a cost-conscious intervention likely to result in a population-wide shift toward early detection and better survival rates from breast cancer.

Keywords Breast cancer · Low- to middle-income countries (LMIC) · Screening · Clinical breast examination (CBE)

Introduction

Breast cancer is the most common cancer and a leading cause of cancer death among women living in low- and middle-income countries (LMIC) despite declining mortality in high-income countries (HIC) [1, 2••]. Over 500,000 new global breast cancer cases are projected by 2030, with a higher incidence in LMICs [3]. The rising morbidity and mortality from breast cancer in LMIC is fueled by a number of factors including late presentation, poor access to medical care, and less than optimal diagnostic and therapeutic capabilities on the ground. In addition, increasing reports of aggressive subtypes in younger populations potentiate the impact of these inequities in some populations. Breast cancer in women in the developing world tends to present earlier than in affluent nations and seems to have a higher rate of triple negative and high-grade histology. The causal etiology for this geographic/ethnic variation remains to be studied [4].

Screening Approaches

Reducing the breast cancer burden in LMICs will require multi-pronged efforts, including community awareness, promoting access to early detection, overcoming barriers to accessing the health system, and making diagnosis and

This article is part of the Topical Collection on *Global Breast Cancer*

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treatment more affordable. The availability of effective and affordable treatment can contribute to improved outcomes as women gain confidence in coming forward with their symptoms [5•]. On the other hand, efforts to improve early detection remain a cornerstone for reducing breast cancer morbidity and mortality. Mammography remains the only established imaging means for early detection of breast cancer, yet the evidence supporting routine screening of women in HIC reveals the highest benefit only for women between the ages of 50–69 years [6]. For younger women, the high rate of false positive findings on mammograms and the associated invasive diagnostic procedures negate the societal economic benefit [6].

Many developing countries have adopted North American screening guidelines, despite the lack of adequate resources and financial support to implement and achieve comparable standards [7]. While North American guidelines advocate for mammography as the most effective screening approach, most developing countries do not have ready access to the technology, nor the trained workforce needed to perform and interpret mammograms. Data on the use of mammography for LMICs, where breast cancer appears to present earlier and with a more aggressive phenotype, do not exist. To mitigate this, recommendations from the WHO advocate against population-based screening mammograms for low-resource settings, especially those with weak health systems [8•]. WHO guidelines support universal access for women with symptomatic lesions and encourage the use of clinical breast examination (CBE) as a screening modality [8•]. In HIC, early detection is targeted at asymptomatic women. Whereas in LMIC, there is some data that supports promoting clinical breast examinations for symptomatic women as a strategy to down-stage and improve outcomes [5•, 9].

In this paper, we present perspectives from three countries and report on efforts to address the burden of breast cancer through screening and early detection programs. The first case study describes a community-based program in Tajikistan, an impoverished country in Central Asia where local health care providers were trained to provide CBE for asymptomatic women as a means to introduce breast cancer screening into routine care and address high mortality rates from breast cancer. The second case study is from Kenya and describes a hospital-sponsored screening where a robust marketing campaign provided widespread information on breast disease and trained health professionals provided CBE as part of breast cancer awareness campaigns for women. The third case study is from Pakistan where we describe a combination of approaches; a national program to provide mammography for eligible women and a university-sponsored program that leverages community health workers for health promotion and CBE for symptomatic women.

Tajikistan

Tajikistan is a landlocked country in Central Asia with an estimated population of over 8.6 million people [10]. The majority of the population lives in rural areas with only one quarter living in urban centers. Tajikistan is a poor mountainous country with one third of the population living below the poverty line and over 1 million of its citizens working and living abroad. As a result, a third of the gross domestic product can be attributed to remittances. Despite a struggling economy, the country boasts a 99% literacy rate and a life expectancy of nearly 70 years, with 40% of the population within the ages of 25–53 years of age [10]. Historically, the healthcare system in Tajikistan has largely reflected the Russian health care system leaning heavily on specialists for care. In the last few decades, the government has been assigning resources and priority to establishing a primary care system re-training specialist to be family doctors and educating the population to utilize the services of primary care providers. Tajikistan has the lowest health care spending per capita in the WHO Euro region [11] with the majority of health spending coming from out-of-pocket spending compared to 28% from government spending [11–13]. Tajikistan, like many other developing nations, struggles with the double burden of disease with both communicable and non-communicable diseases contributing to morbidity and mortality. Sixty-nine percent of all deaths are estimated to be attributed to non-communicable diseases, of which 42% are from cardiovascular disease and 10% are from cancer deaths [14, 15].

Breast cancer is the most common cancer among women in Tajikistan and the highest cause of female cancer deaths [14]. Similar to other resource-constrained countries, limited access and utilization of primary care providers contribute to late presentation, resulting in high mortality. In 2014, the government partnered with a non-governmental organization, the Aga Khan Health Services, to implement a comprehensive community-based breast care program [16, 17]. The program took place in Gorno Badakhshan, a mountainous region of the country particularly afflicted by poverty and isolation. The partnership involved visiting health professionals from the USA working alongside local health care providers in the continuum of breast care—from education to diagnosis and management of detected breast abnormalities. A systems assessment revealed a lack of knowledge among women about breast disease and family doctors with limited proficiency in CBE. In addition, despite the availability of mammography and ultrasound, there was a lack of well-trained operators and clinician interpreters.

The screening program implemented in Gorno-Badakshan utilized the strong network of primary care providers and community health workers to promote annual CBE for asymptomatic women and health education on breast disease. The visiting team of providers trained a cohort of local family

doctors and nurses in clinical breast exams and then conducted a community-wide campaign for breast cancer education and screening. The campaign offered the dual benefit of educating women in the community while the newly trained family medicine doctors were supervised for proficiency by visiting clinicians. Between 2014 and 2017, over 3500 women were screened and a total of 18 women were diagnosed and treated for breast cancer. The six patients diagnosed during the initial campaign in 2014 all had advanced disease (stage III or higher) whereas the majority of the patients diagnosed between 2016 and 2017 had localized disease (stage II). Furthermore, while the first 600 women were screened in conjunction with the visiting providers, nearly 75% of the screen population were independently examined by local family doctors or nurses. With refresher training offered 1 year after the initial campaign, the program demonstrated success in identifying clinical early-stage cancer in addition to demonstrated CBE proficiency of the clinicians and community acceptance of breast cancer screening [17].

Kenya

Kenya has a population of over 45 million, with the majority living in rural areas and just over 40% living in poverty. Life expectancy in Kenya is 64 years. The health care system in Kenya includes three main sectors: public health care providers serve the majority of the population and operate 41% of facilities, the private sector operates 43% of health facilities, and non-governmental organizations run 15% of health facilities. Over 60% of health care expenditure comes from the government and over 25% from out-of-pocket spending [18]. Robust policies reflecting the prioritization of primary health care exist, yet the health care system suffers from inadequate financing, staffing, and limited resources to serve the most vulnerable [18].

Breast cancer is the most common cancer in Kenyan women with nearly 5000 women diagnosed annually [7, 19]. Some data suggests that in African women, breast cancer peaks between the ages of 35 and 45 years, 10–15 years earlier than for western countries [7]. A study at Kenyatta National Hospital showed that over half of the women who presented with breast masses presented with advanced/metastatic (stage III/IV) breast cancer. The Kenyan National Cancer Guidelines recommend an annual screening mammogram combined with a CBE for women between the ages of 40–55 and every 2 years for women aged 56–74 years. Recent studies have suggested that improving overall outcomes and cancer survival in Kenya will require community awareness, age-specific screening, and early treatment programs [20, 21].

We report here on a public-private partnership established to address the dire need for early detection of breast cancer in East Africa. This partnership between the Aga Khan Development Network, local healthcare institutions, civic organizations, and public authorities in Kenya and Tanzania utilized CBE as part of their offering during breast cancer awareness campaigns. The Aga Khan Hospital in Nairobi and Dar-es-Salaam have been conducting breast cancer screening camps over several years as part of their community service effort. This community-based program provided education on breast cancer and used CBE by practicing clinicians as the primary screening tool, escalating to breast ultrasound and/or mammography for abnormalities. In general, the clinical team consisted of physicians actively involved in breast cancer care, nurses trained and experienced in CBE, a radiologist, and a pathologist. Civic organizations including local breast cancer organizations provide informational handouts, held educational presentations in the local vernacular, and held support groups for women with breast cancer. The camps were conducted at local clinical facilities that provided space and logistic support, as well as, awareness lectures, private spaces for CBE, and onsite ultrasound-guided FNA for women with a palpable mass. The programs were promoted through public service announcement in the media, local churches, or mosques and through word of mouth in the local community. All women over 15 years of age were permitted to participate. In some cases, cervical cancer screening was conducted at the same time for women of reproductive age.

Key to the CBE campaign was adherence to a peer-reviewed and evidence-based algorithm for the diagnostic evaluation of identified breast masses. Women with abnormal CBE underwent diagnostic evaluation based upon the algorithm and the responsibility for navigating the women through the clinical process was given to the clinicians affiliated with the local hospitals who had access to radiology, pathology, surgery, and oncology services. Data published by the team revealed that of the 1094 women screened during various campaigns, only 23% had been aware of a lump in their breast. Fourteen percent of women who underwent a CBE had an abnormal exam, and a total of 14 invasive breast cancers were diagnosed (1% of all screened and 9% of women who had an abnormal CBE) [20]. A third of the cancers were detected in women less than 40 years of age [20].

Anecdotal observations support that many women's lives were impacted by the empowerment associated with breast cancer awareness. A wide array of women attended the breast cancer awareness camps and underwent CBE. There was a benefit to the individual in terms of awareness about breast health and a sense of empowerment that came with knowledge. However, the high frequency of non-malignant breast masses in such a mass screening of women poses a dilemma, which could well be addressed with an age-specific approach. However, such a strategy may be seen as discriminatory by the community unless breast cancer awareness and education is also an integral part of such an initiative. Lessons learned need to be incorporated into CBE campaigns while at the same time

significant resources will need to be allocated to implement the guidelines which recommend screening mammography as the primary tool for early detection of breast cancer.

Pakistan

Pakistan has an estimated population of over 200 million, making it the sixth most populous country in the world [22]. Over the last two decades, there has been rapid urbanization of the country with over 35% of the population now living in cities, and the remaining still living in rural areas [22]. The average life expectancy for women is 68.4 years with 22.3% of people living below the poverty line. Pakistan's health care system, which includes a public and private sector, struggles with a lack of resources and a major shortage of health workers, particularly in rural areas. Government spending in Pakistan on health care is minimal with only 0.6% of the GDP spent on health care and only 15% of health care dollars allocated to preventive and primary health care. Unlike Tajikistan, women in the rural areas have a high rate of illiteracy and minimal awareness or education about personal health care issues [9, 23]. In 1994, the government of Pakistan launched the National Program for Family Planning and Primary Healthcare, a program that trained and deployed close to a 100,000 lady health workers (LHW) who live in their respective communities to provide primary health care services to the urban and rural slums [24]. Over the last two decades, this program involving LHW in rural areas has been instrumental in improving maternal and child health. Despite these efforts, the health care system continues to face challenges as the quality of care is largely unregulated, many of these LHW have variable skills, and many areas are inadequately staffed.

Breast cancer in Pakistan is a concern with 1 in 9 women affected by breast cancer and close to 40,000 deaths each year from the disease [25]. Pakistan has high mortality rates of breast cancer when compared to all other Asian countries largely attributed to women presenting with late-stage disease [26]. Factors that appear to contribute to late presentation include inadequate health care infrastructure, sociocultural barriers, economic challenges, illiteracy, and differences in the clinical and pathological attributes of breast disease among Pakistani women. In a recent study by the Aga Khan University Hospital in Karachi, Pakistan, >50% of women with breast cancer presented to their institution with locally advanced/metastatic disease (stage III/IV) [9, 27]. In the same study, more than 25% of women in Pakistan presented with breast cancer under the age of 40 and 37% presented with triple negative breast cancer [27]. Patients from the public sector where women present from more rural and underserved areas and are likely to present with an even higher proportion of late-stage disease. Lack of organized breast cancer screening, inadequate breast imaging facilities, and the general disregard toward women's health in a predominantly patriarchal society all contribute to delayed presentation of women with breast cancer [23]. The breast is often associated with sexuality rather than health, and women are deterred from going to hospitals for screenings or to discuss any breast symptoms with their families [28]. Women in rural communities' lack awareness of the signs and symptoms of breast cancer, and even when they initially palpate a breast mass, the lack of other symptoms deters them from seeking health care [29]. Most women present with large palpable masses and axillary adenopathy, or with skin ulceration, fungating masses, and even chest wall invasion. Moreover, inadequate diagnostic facilities close to home, lack of access to physicians, and the costs associated with traveling to larger cities for care dissuade women from seeking any care [29]. One study of 1000 women at a public hospital in Pakistan reported that 50% of women had no knowledge about breast cancer symptoms, 72% did not know how to perform breast self-examinations (SBE), and 44% did not know the significance of a breast mass [30].

Breast cancer awareness and screening program are more concentrated in the larger cities in Pakistan, with funding mostly from philanthropy. Despite the lack of data for LMICs, screening mammography is available at public and private hospitals in larger cities, but at a cost to patients. The Pink Ribbon Campaign introduced in 2004 in Karachi provides free screening mammograms at public hospitals as well as breast cancer mobile mammography clinics [31]. High-risk women and those who meet criteria for screening mammography have access to no-cost screening mammography and are provided brochures regarding signs and symptoms of breast cancer. This campaign is funded by private contributions and was started after the first reports surfaced in 2004 of the high prevalence of breast cancer in Pakistan compared to all other Asian countries. Another program focused on early-detection and down-staging by leveraging the LHW to first teach SBE to women [9]. Women with an abnormal SBE were then referred to the primary health to undergo a CBE by a physician and women with abnormal CBEs were then referred for diagnostic mammography. In this program, 93 women participated in SBE, of which 18 were found to require a CBE and 1 premenopausal woman was diagnosed with breast cancer. Unfortunately, of the 18 women with abnormal SBE, only half followed-up for the CBE possibly resulting in an underreporting of breast cancer diagnoses. The lack of follow-up reflected the number of other factors which influence health

outcomes including family dynamics, cost of care, and fear of the diagnosis [9].

Conclusions

There is convincing evidence from high-income countries that screening mammography augmented by clinical and self-breast examination can improve the early detection of breast cancer and reduce mortality. The greatest risk reduction is for women between 50 and 74 years of age with more modest benefit for screening women between the ages of 40–49 years. Most expert groups now agree that the widespread use of screening mammography in this younger cohort would result in unnecessary imaging and biopsies in women without cancer. A number of studies from LMICs report that a significant proportion of women diagnosed with breast cancer present in this younger pre-menopausal cohort, have higher grade tumors, and many are often found to have triple negative cancers as compared to women in HIC [27, 32, 33]. Screening approaches therefore also need to target this younger cohort, yet widespread mammography risks costly over-testing and identifying many benign tumors. For LMIC with resource-strapped health systems, the stakes are high to identify cost-effective and accessible screening approaches.

Rather than aiming for population-wide screening mammography in asymptomatic women in LMICs, the examples from Pakistan and Kenya suggest that, for starters, an effective and feasible screening strategy should focus on identifying women with breast masses and then ensuring accessible and affordable diagnostic and treatment pathways. Health promotion efforts should be a priority and should focus on educating women on the signs and symptoms of breast cancer and encouraging them to perform regular self-breast exams as a means of self-awareness. As in the Tajikistan example, primary care providers should be well-trained in clinical breast exams and those with concerning breast masses should be referred for diagnostic mammograms and further work-up as needed. This approach, which prioritizes population-wide education and self and clinical breast exams, is a cost-conscious intervention appropriate for LMICs and may well result in a population-wide shift toward early detection and better survival rates from breast cancer. Concerted research efforts to address the global burden of breast cancer will need to focus on bridging the knowledge gap between screening strategies that work in HIC versus those that can be effectively applied in LMICs.

Compliance with Ethics Guidelines

Conflict of Interest Zohray Talib, Farin Amersi, Attiya Harit, and Mansoor Saleh declare no conflicts of interest relevant to this manuscript.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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