**Attitudes towards Breast Cancer in Nigeria: The Way Forward** 

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#### **Abstract**

Nigeria currently has one of the highest prevalence rates of breast cancer and one of the highest rates of death from breast cancer in the developing world. Part of the reasons for this worrisome trend is the persisting mis-conceptions about breast cancer by women which prevent the adoption of evidence-based methods for the prevention and treatment of the disease. The objective of this presentation is to counter the inaccurate perceptions about breast cancer that exist in Nigeria, and to make recommendations on ways to build a better understanding of the disease that would lead to its sustainable prevention and control.

The presentation has been organized in four sections. In the first part, we present data that show that breast cancer is currently the most dominant cancer among women in Nigeria; and that it is the most common cause of death from cancers in women. We present results of research papers from various parts of the country to explain some of the background reasons for this trend, one of which includes the inadequate health seeking behavior for the disease by women. In the second part of the presentation, we document the attitudes and perceptions of women regarding the causes and methods of prevention, which bear negative consequences on early health seeking for the disease. In the third part of the presentation, we document the true facts about the causes, prevention and curative methods for breast cancer based on the currently available evidence. We posit in this section that although the causes of breast cancer are still not

fully known, early recognition and treatment of the disease can substantially increase the number of women who survive the disease.

In the final and concluding part of the presentation, we make substantive recommendations on ways to improve community awareness on breast cancer in Nigeria in accordance with successful efforts that have been applied in other parts of the world. We believe that the efforts of organizations such as the Breast Cancer Association of Nigeria (BRECAN) in building awareness about breast cancer is an effective and potentially impactful intervention for attaining sustainable reduction of breast cancer disease burden at scale.

I feel highly honored to be invited to deliver this paper at the 20<sup>th</sup> Anniversary of the Breast Cancer Association of Nigeria (BRECAN). While congratulating BRECAN and its management for this milestone achievement, the phenomenal impact that this frontline organization has made in mobilizing national activism for the prevention and management of breast cancer cannot be over-emphasized. Today, BRECAN is one of the best examples of the critical role that non-government organizations can play in this country if they are properly integrated into development planning. There can be no doubt that BRECAN has shown extreme passion, devotion and commitment to educating women about the ill-effects of breast cancer, a worthy cause which it pursues relentlessly and vigorously. The number of persons who may have been reached and who have benefitted directly or indirectly from the messages of BRECAN may never be accurately known. But, there can be no doubt that this organization has stamped its footprints in the sands of time, and has provided critical benchmarks with which best performing organizations in health and social development will be measured in this country for many years to come.

I wish to specially congratulate the Founder of BRECAN, Her Excellency Arabinrin Betty Anyanwu-Akeredolu for her great leadership qualities, resilience and resourcefulness, which has led BRECAN to this stage. She is a great example of what can be achieved for the country when women are given their rightful place in society, especially in the

political configuration of our dear country. A few days ago, a friend of mine in-boxed me in my Face Book account requesting me to name the person I thought would be an ideal President of Nigeria. My immediate response was that in this era of change, we should look for a woman rather than a man. On further reflection, my thought focused singularly on the founder of BRECAN, Her Excellency Arabinrin Betty Anyanwu-Akeredolu, who I have met on a number of occasions. As a mind reader and social psychologist, I have come to identify Her Excellency as a frontline patriot and visionary, and a highly intelligent mobilizer who will stop at nothing but to see to the social transformation of this country when she believes in an issue. Indeed, when I hear of re-structuring these days, what comes to my mind is *political re-structuring*, such that a woman who is visibly progressive on matters relating to development can become the President of our country. I am sure if that happens, things will change for this country, and we will then be able to think of what would unite us rather than things that would divide us.

#### Introduction

Breast cancer is currently one of the most unresolved public health challenges facing Nigeria's health care system. The World Health Organization (WHO)<sup>1</sup> estimates that about 250,000 cases of breast cancer are seen each year in Nigeria. Of these, nearly 10,000 deaths occur, which account for the highest numbers of death from breast cancer in any African country each year. Furthermore, recent evidence suggests that there is a trend towards an increasing incidence of breast cancer in Nigerian women, due probably to decades of inaction in the country to deal with the problem. Among women who experience breast cancer, the case fatality (i.e. proportion of women with the disease who subsequently die from it) is higher in Nigeria as compared to other countries in Africa and internationally. Estimates indicate that whereas up to 85% of women with breast cancer survive five years after treatment in the United States, only 10% of treated women do so in Nigeria. This is largely because a large proportion of women with breast cancer in Nigeria seek treatment at late stages of the disease, when treatment is cumbersome and largely ineffective. Reports indicate that up to 75% of women with breast cancer in Nigeria seek treatment in late stages 3 and 4, when the disease has progressed too far for any treatment to be effective. There are known

methods for the early diagnosis of the disease, which are unknown or largely disregarded in this country. By contrast, women in the United States are more likely to under-go periodic examinations which result in earlier diagnosis and therefore earlier and more effective treatment of the disease.

# **Delay in Treatment of Breast Cancer**

For women with symptomatic breast cancer, primary delay in treatment seeking (defined as an interval greater than 3 months from the time of detection to time of effective treatment) has been shown to be associated with increased tumor size, and poor long-term survival of patients. Available evidence suggests that about 20-30% of women in the UK and other developed countries wait for at least 3 months before they seek treatment<sup>2</sup>. By contrast, up to 70% of Nigerian women wait for periods exceeding 3 months before they seek treatment<sup>2</sup>. This is again largely due to inadequate knowledge, but also due to wrong perceptions and beliefs about the disease, which I will elucidate further in the course of this presentation.

Breast cancer often presents most commonly as a *painless breast lump*, and in a few cases as *non-lump symptoms*. Because in most cases, the breast lumps are not painful, women are likely to ignore the disease at the early stages until it progresses to an advanced stage. Also as a result of this "insidious" method of presentation, women may be more likely to seek inappropriate and non-effective methods of treatment at the initial stage rather than effective treatment.

There are three stages in the prevention and management of breast cancer. The first stage is to prevent the disease from occurring in the first place. This stage also called *primary prevention*, is the best option, but is not always guaranteed to succeed since the cause of the disease is still not known with accuracy.

The second stage, if primary prevention fails is the early detection and treatment of the disease, which I will refer to here as *secondary prevention*. This means that the disease has already occurred, but it must be prevented from spreading to other parts of the body so as to improve the chances of survival for the patient.

Secondary prevention (early detection and treatment) is currently the best strategy for prevention of severe morbidity and mortality associated with breast cancer. This approach is to ensure that all women of reproductive age regardless of whether or not they have a family history of breast cancer will undergo periodic screening for the disease. The three screening methods recommended for breast cancer are 1) breast self-examination (BSE); 2) clinical breast examination (CBE); and 3) mammography. However, there is evidence that these methods are currently not well used by Nigerian women due to the hindrances mentioned above.

The third stage is *tertiary prevention*, which is rehabilitation of women who have developed active and severe disease. There are still several lines of treatment of breast cancer disease, but they are expensive and very intensive, with no certainty that they would succeed in saving the life of an affected woman on the short and long term. These include expensive breast surgery, chemotherapy, and radiotherapy. At the end, these methods may be only palliative and designed to prolong the life of the woman for a few more years.

It is therefore clear that if the current trend towards increased incidence and prevalence of breast cancer and the rising case of deaths from the disease in Nigeria must be reversed, we have to focus on primary and secondary prevention. Tertiary prevention will be too late to make any appreciable impact on the burden of the disease.

# Research into social perceptions of Breast cancer

Getting women to embrace primary and secondary prevention of breast cancer is the major challenge facing the control of the disease in Nigeria. There is evidence that part of the reasons for failure of primary and secondary prevention is the poor knowledge of women about the diseases and their predilection to latch on notions of disease causation that are incorrect and sensational rather than those based on real time scientific evidence. In 2006, my colleagues and myself at the University of Benin<sup>2</sup> conducted a house-hold survey of 1000 women in Benin City to elicit information on their knowledge, attitudes and practice of breast cancer, and their perceptions of the causes and treatment methods for the disease. To our knowledge, this has been one of

a few studies that investigated women's perceptions about the disease in our context. The results showed that a lot of work still needs to be done to create increased awareness about breast cancer among women as a way to improve the management and reduce the burden of the disease in this country. We asked the women questions and compared their responses against the known scientific facts and evidences about breast cancer. The summary of the results presented below showed that in all domains of knowledge, attitudes and practices, Nigerian women did poorly, a situation that needs to be urgently addressed.

# Women's knowledge of breast cancer

Although the cause of breast cancer is not known with certainty, several predisposing risk factors have been identified. These include being a woman, older age of women, genetic predisposition (i.e. family history of breast cancer), and exposure to harmful chemicals. Other risk factors include being over-weight, lack of physical exercise, smoking, eating unhealthy foods, and not breast-feeding during the reproductive years. In the research we conducted in Benin, we asked several questions relating to women's knowledge of the causes and risk factors for breast cancer. On a scale of 0-100%, the women scored 42.3% on knowledge, which was rather low for an important disease such as breast cancer. Indeed, only 229 of the 1000 women (22.9%) scored 50% and above.

Some of the answers that women gave included the following:

- Only 67% of the respondents knew that breast cancer is the most common cancer in women
- Only 25% agreed that breast cancer occurs in older people
- Only 24% agreed that breast cancer can be inherited
- Up to 40% of the women reported that breast cancer is caused by evil spirits
- Only 21% reported that breast cancer often starts as a painless breast lump. By contrast, 14% did not know the answer to the question, while 52% reported that the lump has to be painful.

• Up to 46% of the women reported that breast cancer is NOT curable.

Further analysis showed that the performance of the women on the knowledge score was strongly correlated with women's education and employment status. Women with higher levels of education scored higher in the breast cancer knowledge score, while those with no education or lower level education scored poorly in the knowledge domain. Also, participants engaged in self-employed and small businesses such as trading, hairdressing and secretarial jobs performed poorly in the knowledge score as compared to those employed in professional jobs. From this analysis, it is evident that emphasis should be placed on providing specific education about breast cancer to women with limited education and those in the lower levels of wealth quintile.

## Attitudes of Nigerian women towards breast cancer

We used the results of women's self-reporting of help-seeking behavior to breast cancer as a way to determine their attitudes to the disease. However, their attitudes were positive as only 8.2% of the respondents reported visiting alternative health practitioners for breast cancer care. Another indicator we used to assess women's attitudes towards breast cancer was their willingness to accept mastectomy (removal of the breast) as a method of treatment. Part of the treatment of advanced cancer is removal of one or both breasts (mastectomy), depending on the extent of the disease. Anecdotal reports suggest that Nigerian women may be unwilling to remove their breasts even when they have advanced breast cancer disease. We investigated this by asking the respondents whether or not they would accept mastectomy as a method of treatment for breast cancer. Nearly 87% of the women reported that they had had information of mastectomy as a form of treatment for breast cancer. Of these, 51% of study participants with lower level education, and 66% with higher level education reported that they would accept mastectomy as a method of treatment for breast cancer. In the logistic regression model, the factors most likely to increase the likelihood that women would accept mastectomy included higher level education and those with higher knowledge score about the disease. By contrast, the women's age, marital status and religion were not significantly associated with acceptance of mastectomy.

However, these data must be interpreted with caution as none of these women had breast cancer at the time the questions were asked. It is possible that women with actual disease will give different answers to the question regardless of their social status. As a clinician, I have seen cases of well educated women who declined mastectomy even with very severe disease, which eventually led to their death.

A colleague of mine recently told me of a highly educated woman with advanced disease who said she would only accept mastectomy "over her dead body". Unfortunately, she experienced auto-mastectomy (i.e. self-removal of the breast) on account of the very severe nature of the disease, before she died. We have also heard of several women who resorted to prayers and treatment with native doctors in order to avoid mastectomy. Unfortunately, none of the women is alive today to tell their stories. By contrast, I am aware of several women who under-went mastectomy who are living extremely useful lives today, on account of the fact that they resorted to the procedure at a very early stage of the disease.

Thus, the refrain should be that a breast that is diseased by breast cancer is a useless and dangerous breast, and ought to be removed.

### The practice of women towards breast cancer prevention

As earlier reported in this paper, primary and secondary prevention are the most important approaches for reducing the prevalence and death rates from cancer. We examined how women sought primary and secondary prevention of the disease by asking questions about their practice of breast self-examination (BSE) and clinical breast examination by a medical practitioner (CBE). Among the respondents, only 35% reported that they practice BSE. Of these, only 70% reported that they do this monthly, while 4% do it once in two months, 24% three to five times a year, and 2% once a year. However, there was no evidence that they carried out the BSE procedures correctly.

When we asked question as to their source of information on BSE, 31% reported that they saw it on television; 27% said they saw the method in publications; while 21% reported that the method was described to them by a medical doctor. Other sources of information for BSE were: Churches/religious groups (8%), women organizations (7%), and Nigerian Cancer Society Programs (6%).

Among the 651 women who said they did not carry out BSE, the reasons they gave included: 1) not having any breast problem (50%); 2) not believing they should (24%); 3) believing that only doctors and nurses should do it (3%); and 4) don't know (8%).

Regarding the experience of clinical breast examination by a medical doctor or nurse (CBE) by the respondents, up to 91% reported not ever doing CBE. Reasons reported by the women for not doing CBE included not having breast problem (63%), not knowing that it should be done (32%), and don't know (5%).

Therefore for both BSE and CBE, not being aware of the procedures were the dominant reasons that women gave not practicing these prevention methods for breast cancer. There is therefore a need to focus on awareness creation and advocacy as ways to increase women's access to prevention methods for breast cancer.

### Global review of barriers to treatment of breast cancer among black women

The results in Nigerian women are consistent with the global experiences of black women on breast cancer prevention and treatment. A systematic review conducted by Jones et al, 2014<sup>3</sup> reported 18 studies published in English in developed countries that identified five domains of concerns that prevent black women from seeking early treatment and prevention methods for breast cancer across the studies. These were: 1) knowledge; 2) empowerment and confidence; 3) trust in health care system; 4) quality of relationships with health care professionals; and 5) practical service barriers.

The identified knowledge domain included low awareness of cancer symptoms and/or personal risk, poor symptom awareness and knowledge of risk factors/personal risk, and not recognizing significance of cancer symptoms. Empowerment and confidence consisted of 1) women not making time to check for and/or present with symptoms; 2)

the lack of partner support, or wrong advice from partners; 3) stigma, taboo and fear; and 4) religiosity.

As for "trust in the health care system", the summary of the findings included a large proportion of black women believing that breast cancer can be easily treated – sometimes, women use inadequate treatment such as antibiotics, which delays the application of the correct treatment. Also, the report showed that some women are often afraid of the conventional types of treatment (mastectomy, etc.)

As for "quality of relationships with healthcare professionals", there were concerns by women in the report about interactions with doctors, while many reported that they lacked confidence dealing with healthcare professionals. Practical and service barriers raised included financial burdens and perceptions of access to healthcare services.

#### Recommendations

The results of this study in Benin City and the review of the global literature reported above indicate that women have very poor knowledge of breast cancer prevention and treatment, which account for their low utilization of services. This result has similarly been reported in more recent studies conducted in both rural and urban parts in the different parts of the country<sup>4, 5</sup>. This partly explains why up to 70% of Nigerian women with breast cancer present in very late stages of the disease<sup>2, 4</sup>.

Research has also shown that even professional nurses and doctors who ought to be role models on issues related to breast cancer prevention also have limited use of prevention methods for the disease. In a study conducted by Akhigbe and Omuemu in Benin City (2009)<sup>6</sup> among female health workers, although many had good knowledge of mammography as a screening method for breast cancer, only 3.1% of the respondents had ever used the method themselves. Similar results were obtained in studies conducted in Lagos State<sup>7</sup>, where only 8% of female health workers had ever used mammography. The results for northern Nigeria were 9% of female health workers using mammography in Sokoto State<sup>8</sup>.

In rural northeast Nigeria, similar poor knowledge had been demonstrated in a research conducted by Omotara and colleagues in Borno State<sup>5</sup>. Only 58% of women in this region had ever heard of breast cancer; 21% thought it is due to spiritual causes; while only 39% of the respondents had ever used BSE.

The results of these studies suggest a need to build the awareness of Nigerian women and their care-givers in preventing and treating breast cancer using evidence-based methods.

Health information and promotion is currently seriously lacking in Nigeria, and is one of the important bottlenecks to be addressed if we are to bring good and effective health care to our people. As long as women have limited knowledge about breast cancer, so long will they not be able to take appropriate measures to prevent the disease through regular screening and treatment in its early stages.

The recommended screening methods for the early detection of breast cancer are **BSE**, **CBE and mammography**. Of these BSE is of doubtful effectiveness, as women cannot be relied upon to do it correctly. By contrast, CBE and mammography have been shown to be more effective in diagnosing breast cancer at the early stages<sup>2, 9</sup>. The American Cancer Society<sup>2</sup> recommends that women aged between 40 and 49 years should undergo a CBE and mammography every one or two years. The Society also recommends that women older than 50 years should undergo annual CBE and mammography. It is best to adopt these recommendations for Nigeria, and also to ensure that women have access to and demand such preventative services.

Awareness Creation and Information Dissemination: Arising from the above analysis, the major recommendation going forward is that emphasis should be placed on encouraging women to practice BSE, CBE and mammography on a regular basis. Health education should be targeted at women using various sources of information including behavioral change communication methods (posters, leaflets and factsheets) old media (radio and TV) and the social media (Facebook, twitter, istagram, etc.). These sources of information are critically important as means of reaching women with

essential information about breast cancer. Although non-governmental organizations such as BRECAN have regularly disseminated information on breast cancer, other governmental agencies (Women Affairs Ministries, Ministries of Health, Local Government Councils, Primary Health Care Development Agencies, etc.) must get involved in order to achieve greater effectiveness and impact at scale. Other NGOs also need to get involved in this endeavor as breast cancer is currently a major scourge for women in Nigeria.

Training of religious leaders: In view of the impact of religion on women's perceptions about the disease and their use of services, it would be relevant to build the capacity of religious leaders to counsel women about the disease. It's would be particularly important, so that religious support and prayers become integrated into the management of the disease, Prayers should be included but not exclusively used as it is commonly said that "Heavens help those who help themselves". An advice given to a woman by a religious leader to seek help while prayers continue will help women to come to real terms about the use of appropriate methods to treat the disease.

Training of health workers: The training of health workers would also be an important and essential intervention to help Nigeria's health system to tackle the challenge of breast cancer. Health workers training will help in many ways. First, it is generally recognized that health workers are the most important source of information on breast cancer to women. Thus, educating health workers (who apparently currently have poor knowledge of the disease) will help these workers to interrogate their patients about the disease. There are several opportunities that health workers can use to educate women about breast cancer, and to perform CBE. These include when women make gynecological consultations, and during antenatal and postnatal care. These opportunities can only be taken effectively when health workers know more about the disease.

Secondly, through training health workers can work towards integrating breast cancer awareness education into already existing health educational programs. Thirdly, as health workers are the best advocates for health and well-being, they should be trained

to participate and sponsor health talks, seminars and workshops targeting various audiences. Through evidence-based advocacy, health workers can help to change the mindset of policymakers, so they can provide sufficient resources for the prevention and treatment for breast cancer.

*Improved breast cancer screening services:* The current lack of a purposefully implemented breast screening program in Nigeria is worrisome. CBE and mammography are the most effective screening methods but they are presently not implemented at the health systems level in the country<sup>10, 11</sup>.

There is evidence, for example that women will be ready to have their breasts examined by a doctor regardless of the sex of the doctor<sup>10, 11, 12</sup>. So, it is important that a breast screening program that focuses on CBE as the entry point, followed by mammography is urgently needed in the country.

To date, the number of health facilities with functional mammography machines and programs in the country is not known with accuracy. Thus, as a first step it would be important to conduct an audit of available mammography services in Nigeria. Thereafter, efforts should be made to correct the identified gaps and then to implement a breast cancer screening service at both local, state and national levels. I am convinced that with the caliber of Her Excellency, Arabirin Betty Anyanwu-Akeredolu at the helm of affairs, Ondo State will lead other States of Nigeria in providing this essential service.

Improved breast Cancer curative services: Also, it is widely known that curative services for breast cancer are not fully optimal or functional in Nigeria. Curative services include surgery (lumpectomy or mastectomy, chemotherapy and radiotherapy (for more extensive disease). It is important that we improve the quality of available breast cancer treatment services in the country and encourage women with the disease to use the services. Again, advocacy for improved demand and supply of effective breast cancer treatment services is an approach that can be championed by BRECAN, with Ondo State opening the gateway for other States in the country to follow.

### **Conclusions**

In summary, it is evident that there is currently extremely low level of awareness about breast cancer by Nigerian women. This is due to the inadequate knowledge of breast cancer by vulnerable women, and the poor integration of breast cancer prevention and treatment into Nigeria's health care delivery system. Breast cancer is the most common cancer and is the most common cause of death from cancer among Nigerian women. Whereas death from breast cancer has declined in many parts of the developed world, death rate from the disease has continued to rise in the country. As the right to health is a fundamental right of all citizens, this presentation is a call to action to all Nigerian governments to take steps to reverse the trend. Specific measures such as providing evidence-based information to women to demand breast cancer prevention services and the improved supply of qualitative breast cancer prevention and treatment services would be critical in efforts to reduce the burden of breast cancer disease and deaths in Nigeria. We commend the pioneering efforts of BRECAN for championing the cause of breast prevention and treatment in Nigeria over these past years. We wish the organization happy 20th birthday and a most eventful future.

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