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BREAST CANCER IN INDIA: REVIEWING AWARENESS OF SELF-CHECKS, SCHEMES AND ADVOCACY EFFORTS

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ABSTRACT

India has witnessed a steady rise in the incidence of breast cancer. The mortality rates of breast cancer increase significantly as the disease progresses into later stages. This makes early detection, screening, and treatment extremely crucial. India has witnessed high rates of economic development in recent years, which has been accompanied by the development of technology in several fields, including medicine. However, such development has not trickled down to rural regions of the country. Not only do these regions suffer from comparatively higher rates of illiteracy and poverty, but the state of public healthcare is also inadequate to serve a population as high as India's. The stigma around women's health and hygiene that prevails in a patriarchal society like India adds to the barriers that women need to clear to access healthcare, which is widely recognized as a basic human need. This paper has explored the reasons behind the healthcare's sectors inability to deal with the increasing rates of breast cancer in the country. It also provides recommendations that seek to improve the present scenario.

Keywords: Breast cancer, Awareness of self-checks, Healthcare, Rural regions

INTRODUCTION

Breast Cancer is a disease that involves abnormal growth of cells in the breast tissue. Its primary causes include obesity, lack of physical exercise, consumption of alcohol, hormone replacement therapy, ionizing radiation, and older age. About 10% of cases co-relate with the history of breast cancer in the family which shows that genes inherited from one's parents also cause breast cancer. The primary symptoms of breast cancer include bone pain, swollen lymph nodes, yellow fever, and shortness of breath.

Breast Cancer is the most common form of cancer that affects urban women in India and the second most common form of cancer that affects rural women in India (National Cancer Registry Programme, 2001). The prevalence of this disease has been consistently increasing over the past half-century, and it is estimated it has risen by 50% between 1965 and 198. On an estimate, there

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are over 100,000 new cases of diagnosis of breast cancer every year in India. The standard rates of incidence are variable across India and are dependent on the region, ethnicity, and religion of women. For example, the Parsi community of Mumbai showed the highest rates of incidence at 48.3 per 100,000 women in the country. Breast cancer has been reported to occur a decade earlier in Indian patients as compared to their western counterparts. While the majority of breast cancer patients in western countries are aged between 60 to 70, that is the postmenopausal stage, about 50% of Indian patients are in the premenopausal stage. About 80% of patients in India are less than 60 years old, with the average age of diagnosis ranging from age 40 to 50 (Agarwal, Pradeep, Aggarwal, Yip & Cheung, 2007).

India is a country where there economic and social inequality exists alongside religious, cultural and ethnic diversity. This creates high levels of inequality in access to healthcare that women have, across the country. The degree of development of medical infrastructure and facilities is also extremely lopsided between urban and rural regions, as well as amongst various states in India. The presence of myths amongst uneducated masses of rural India combined with the lack of outreach of awareness programs leads to diagnosis only at advanced stages of the disease, hence reducing the rate of survival. The general ignorance of female health and hygiene in the patriarchal society of India has also led to the sidelining and de-prioritization of breast cancer in the Indian healthcare sector. The quality of care available to patients of breast cancer is extremely heterogeneous. India is home to private hospitals that provide treatment for breast cancer that is on par with the best facilities in the world. However, these hospitals are only found in metropolitan cities and are unaffordable for the majority of the population. Therefore, the vast majority of breast cancer patients, especially those who lie at the bottom of the economic or social pyramid have to go through inadequate and sub-standard treatment in government-run hospitals. There is a paucity of infrastructure, human and financial resources, and research in hospitals operated by the government, with some exceptions such as the All India Institute of Medical Sciences.

BACKGROUND

The first observable symptoms of breast cancer is typically a lump that feels different from the rest of the breast tissue. More than 80% of breast cancer cases are discovered because of the presence of this lump (Merk Manual of Diagnosis and Therapy, 2003). Lumps found in lymph nodes located in the armpits can also indicate breast cancer. Other symptoms include yellow fever, pain around the breast and armpit and swelling around the armpit or beneath the collarbone. The staging of breast cancer depends on the size of the tumor, whether or not the tumor has spread to lymph nodes in the armpits, and whether the tumor has metastasized (i.e.

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spread to a more distant part of the body). Stage 0 represents the pre-cancerous or marker stage, the cancer is restricted to the breast and lymph nodes in the armpits in the first three stages.

During the 4th stage, cancer spreads to other parts of the body hence worsening the prognosis and reducing the chances of survival or remission (American Society of Clinical Oncology, 2012).

There are two types of risk factors of breast cancer, modifiable risk factors, which can be changed by human behavior (obesity, consumption of alcohol) and fixed risk factors, which cannot be changed (age, biological sex). Age is one of the primary risk factors, as the risk of breast cancer increases as women grow older. Genetics, specifically, the presence of BRCA mutation amongst women increases the risk of breast cancer by 60% to 80% (McGuire, Malone, Daling, Thompson, O'Brien, Francisco & Ostrander, 1998). Rural Indian women are, however, most vulnerable because of the presence of many risk factors that act against them. Exposure to Aromatic Amines and DDT occurs because of their usage in pesticides and fertilizers. Women in rural India, most of whom are employed in agriculture are constantly exposed to such substances which increase the risk of breast cancer. They also have a higher mortality rate because of multiple reasons. This includes higher rates of poverty in rural India, the lack of diagnostic facilities in villages, availability of only sub-standard treatment after diagnosis and the presence of sociological factors such as patriarchy and untouchability which increases hurdles that women, especially those from lower castes have to access medical care.

Treatment of breast cancer depends on various factors, including the stage and level of progression of cancer and the person's age. Treatments tend to be more aggressive when the cancer is at a higher stage or there is a higher risk of recurrence of cancer following treatment. Breast cancer is usually treated with surgery, chemotherapy, radiation therapy, hormonal therapy or a combination of these procedures. Chemotherapy is used to destroy fast-growing cancerous cells, but the usage of this procedure also kills fast-growing normal cells, which may cause serious side effects, including damage to the heart muscle. However, access to all medical facilities is extremely limited, mostly because of financial restrictions, social barriers and a general lack of their presence. Government schemes have only intended to reduce the financial burden on the poor, without dealing with other equally important problems. For example, ‘The Health Minister’s Discretionary Grants’ offers up to a maximum of Rs. 50,000 to poor patients to assist with a part of the hospitalization/ treatment in government hospitals in cases where free medical facilities are not available. At the same time, there are only 210 institutions in the country that possess radiotherapy installations, most of them being located in urban regions (National Portal Content Management Team, 2011). This implies that most rural poor don't even have access to the ‘Health Minister’s Discretionary Grants’ because of geographical, social and

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economic barriers combined with the abysmal quality of infrastructure and unavailability of state healthcare infrastructure and services. India only has about 100 large community hospitals associated with government medical colleges for a population of more than a billion people, where healthcare is free and where the majority of the nations' cancer patients are treated.

However, oncologic services are basic or nonexistent in many of these hospitals, where the majority of breast cancer patients are treated only surgically. The fact that this disease becomes more lethal as it progresses into its later stages makes the need to improve diagnostic and treatment facilities in rural areas even more urgent.

DISCUSSION

Breast Cancer can be prevented by the use of screening, improvements in lifestyle, pre-emptive surgeries and medication. Breast cancer screening refers to testing otherwise-healthy women for breast cancer to achieve an earlier diagnosis. It operates under the assumption that early detection is directly related to lower mortality rates and provides access to better treatments at the right time. One of the most common ways of screening breast cancer is mammography which uses low energy X-rays to examine human breasts. However, the use of screening, especially mammography is often a subject of debate, because of the risks associated with this procedure. Cochrane Reviews are systematic reviews of primary research in human health care and health policy and are internationally recognized as the highest standard in evidence-based health care. The Cochrane analysis of breast cancer screening indicates that it is "not clear whether screening does more good than harm". According to their analysis, 1 in 2,000 women would have their lives prolonged by 10 years of screening, while 10 healthy women would undergo unnecessary breast cancer treatment. Additionally, 200 women would suffer from significant psychological stress due to false positive results (Jørgensen & Gotzsche 2013). Other criticism includes the risk of overtreatment, radiation exposure, radiation exposure, and cancer scares associated with breast cancer treatment (Mulcahy, 2009). However, there have been significant improvements in medical technology and enhancement in procedures. Multiple organizations including the U.S. Preventive Services Taskforce, American College of Radiology and the European Cancer Observatory recommend the usage of mammography for women in the later stages of their lives (U.S. Preventive Services Taskforce, 2016). The incidence of breast cancer is lower in India than that in high-income countries. However, the number of deaths attributable to breast cancer in developing countries like India is double the number in high-income countries (Agarwal & Ramakant, 2008). This is can be attributed to lower rates and delaying of diagnosis. India lacks a national or regional breast cancer screening program. This is a part of the larger problem of a lack of state investment in breast cancer diagnosis and treatment.

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Radiotherapy is primarily available in private hospitals and in the 21 regional cancer centers established under India's national cancer control program (Dinshaw, Shastri & Patil, 2005). The lack of timely screening leads to delayed treatments and the progress of cancer into higher stages where mortality rates are higher.

Women can reduce the risk of breast cancer by maintaining a healthy weight, reducing alcohol use, increasing physical activity, and breastfeeding. A high intake of citrus fruit has been associated with reducing the risk of breast cancer by 10% (Song & Bae, 2013). Other foods that can reduce risk include soy-foods and n-3 fatty acids (Zheng JS, Hu XJ, Zhao YM, Yang J & Li D 2013). Due to the absence of adequate research and information dissemination by the government, NGOs like the Pink Initiative and Prashant Cancer Care Mission run programs related to breast cancer awareness, prevention, diagnosis and treatment at the grassroots level.

Corporates also partner with NGOs as a part of their corporate social responsibility initiative. Tata Trusts, which is controlled by the conglomerate Tata group, along with Prashanti Cancer Care Mission and Swasth India Foundation launched an initiative titled '#LosingIsNotAnOption', which was India's largest breast cancer screening drive. Launched in 2016, it targeted over 2.3 lakh women in Pune (Tata Trusts, 2016).

The breast cancer movement of the 1980s and 1990s emerged out of the larger feminist movements and women's health movement of the 20th century. The pink ribbon is the most prominent symbol of breast cancer awareness and is synonymous with breast cancer movements. The breast cancer culture or the pink ribbon culture emerged out of the breast cancer movement as a set of activities, attitudes, and values that surround and shape breast cancer in public. It is characterized by shared values are selflessness, cheerfulness, unity, and optimism. However, wearing or displaying a pink ribbon has been criticized because it has no practical positive effect. It has also been criticized as hypocrisy because it has been re-appropriated by people who wear the pink ribbon to show goodwill towards women with breast cancer but simultaneously oppose these women's practical goals, like patient rights and anti-pollution legislation and by corporates who use the pink ribbon campaign to promote products such as alcohol that increases the risk of breast cancer amongst women. It is also criticized for being a distraction from actual societal and scientific development and for perpetuating gender stereotypes about women. Despite criticism from the west, Breast Cancer India which is supported by The Pink Initiative has been responsible for positive changes and increased awareness of breast cancer in Mumbai. They aim to provide comprehensive information on breast cancer, and the scenario in India to guide women on prevention and early detection. They are also responsible for starting the first online community for breast cancer in India, to encourage patients and their families to share problems,

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solutions, and experiences with breast cancer. This helps develop a sense of solidarity as the treatment of breast cancer involves a lot of emotional turmoil.

Generating awareness and disseminating information is imperative for early diagnosis and better prognosis. This helps is breaking down myths and stereotypes around the illness, especially in rural India, which has lower rates of literacy. Over the past decade, brands including Lux, Philips, and Avon have partnered with NGOs and celebrities to spread awareness about breast cancer on social media and on the grassroots level (Srivastav, 2018). However, there is a growing need for governments to take upon themselves the responsibility of educating citizens through the use of state machinery. Children should be introduced to breast cancer in school as a part of their curriculum. This method has proven effective in India with AIDS, as there have been positive changes in people's understanding of the disease since its inclusion in the school curriculum several years ago (Trivedi, 2014).

Beyond awareness, the government must also develop medical infrastructure in rural areas that is capable to support breast cancer screenings. These checks should be free, as most rural women don't have the financial ability to undertake treatment, let alone preemptive screenings. Funding such development has been an issue of debate. One of the major differences between the health sector in India and most European countries is that in India, the government has a dominant role and charities and commercial companies have a very minor one. The investment that the private sector undertakes in research and development in minimal (Sullivan, 2014). This puts a humongous burden on government agencies, which is impossible to fulfill even in countries with smaller populations. The government should impose provisions that force pharmaceutical companies to undertake research and investment in rural areas out of the profits that they generate whilst operating in the country. Similar provisions exist under the label of Corporate Social Responsibility, which mandates certain companies (as defined by the Companies Act) to spend a part of their revenue in activities related to areas such as education, poverty, gender equality, and hunger.

CONCLUSION

The key to improving mortality rates of breast cancer in India rests on three pillars- research, awareness, and infrastructure. More emphasis and value needs to be placed on cancer research by policymakers in the government. The creation of links between research and policy agendas is imperative to deliver an affordable cancer care system in India (Marquez & Dhillon, 2014). Moreover, information about such research and policy needs to be adequately disseminated to the public, especially women living in rural areas to effectively implement health policy. Lastly, there needs to be an increase in investment in the rural health sector of India from both private and public sources to provide screening and treatment facilities free of cost. There needs to be a

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collective effort from government and non-governmental bodies to break the larger social stigma attached to the health and hygiene of women.

The rates of breast cancer in India have been progressively increasing over the last few decades especially amongst younger women (Okonkwo, Draisma, Kinderen, Brown & Koning, 2008) despite the growing technological innovations in the health sector and steady rates of economic development. This is a reflection of the ignorance of the government and greed of the private healthcare industry. Collective efforts need to be undertaken by the state and central government; grassroots non-governmental agencies and charities; healthcare companies and private hospitals; and individual citizens to provide the basic need of access to cheap healthcare, which is presently absent for the majority of women. This is needed not only to reduce mortality rates of breast cancer but also provide a sense of security and safety to women.

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