

Breast Cancer and Higher Mortality Rate in Kashmir: A Socio-Cultural Explanation

Mehnaz Hassan

Abstract— A vague picture of life and death arise in the mind casting a shadow of fear and sorrow while one recounts the disease called cancer. Since the last few decades, Kashmir is experiencing a rising graph of breast cancer patients. Cancer is synonymous to death in Kashmir. Breast cancer, the most frequent cancer of women in the world is the second leading site of cancer in females in Kashmir. But more tragic is that Kashmir has a higher death rate of breast cancer patients than that of rest of India. This is partly due to the lack of awareness regarding this dreaded disease and partly due to the late presentation before a practitioner. The problem gets aggravated due to lack of resources and hence termination of or delay in proper treatment. All this amounts to the lesser survival years of patients. The high mortality rate of breast cancer patients in Kashmir can be attributed to its socio-cultural structure. The deeply rooted cultural values and traditions with respect to women folk become an obstacle in timely diagnosis and treatment of the disease. The present paper brings to fore the socio-cultural factors leading to the lesser survival years and hence higher death rate of breast cancer patients in Kashmir valley.

Index Terms— Breast cancer, survival years, socio-cultural structure, traditions, diagnosis, practitioner.

I. INTRODUCTION

The rising global incidence of malignant diseases as documented by World Health Organization is an issue of serious concern, particularly in the developing countries where the increase seems to be more preponderant [1]. Despite the great progress made in the diagnosis and treatment of cancer, poor countries face lack of protective measures. Estimates show that 50% of the people suffering from cancers are from these countries [2].

Cancer is one of the most dreaded diseases in the world. Of the ten million new cases diagnosed every year, more than half are from developing countries. While it is a leading cause of death among all racial and ethnic groups, the mortality burden is not distributed evenly among the various groups [3]. Persons of low socio-economic status bear the greatest cancer burdens.

The incidence of cancer is rising every year, and this is attributed to the changes in lifestyle and increase in life expectancy. Cervical cancer and breast cancer are the commonest cancers among the female population of India. In the young age group, the high incidence of colorectal cancer is a matter of concern. Malignancy of gastrointestinal tract is the most common among cancer patients in the Kashmir region [2].

Cancer of breast is a disease that instills a feeling of dread and fear in many women. Not only is it a life-threatening

disease, but it affects a part of the body that is central to women's sense of womanliness and femininity [4]. In poor countries, maximum of the breast cancer patients die from the disease. Breast cancer is the most common malignancy affecting women worldwide [5]. It is globally one of the leading causes of morbidity and mortality in women [6]. Globally, the devastation that befalls women diagnosed of breast cancer remains inestimable. Early detection remains a major effective approach that should be employed to combat the disease [1].

To the best of my knowledge, the present study is the first sociological study of breast cancer in Kashmir. No doubt, a lot of research on breast cancer has been done in the Valley but the thrust has been on the medical dimension which does not help much in framing long term policies and decisions for the patients. The social aspects of breast cancer need to be thoroughly studied so that such policies and programs would be framed for them which are inclusive and particularly feasible to women.

II. BREAST CANCER IN INDIA

The incidence of breast cancer is low in India, but rising. Breast cancer is the commonest cancer of Indian women and accounts for 27% of all cancers in women [7]. The incidence of breast cancer in Indian women is much lesser than the counterparts in industrialized nations. Nonetheless, breast cancer has emerged as the commonest cancer in urban Indian women, and second commonest to the cancer of the uterine cervix in rural women [8]. For every 2 women newly diagnosed with breast cancer, one woman dies of it in India. [7].

About 75,000 new cases are reported in Indian women every year [9]. Since more patients in India turn up in later stages, they do not survive long irrespective of the best treatment they may get, and hence the mortality is fairly high. According to the Breast Cancer India, more than 50% patients of breast cancer present in stages 3 and 4, and outcome is not as good as earlier stages, however aggressive the treatment may be. There are lots of reasons for late presentations including lack of awareness, shyness on part of patients, social stigma, ignorance of doctors (patients present on time, but doctors are not aware and they delay treatment), and many other causes.

III. BREAST CANCER IN KASHMIR

Every year, there is a marked increase in the number of cancer patients registered in the Valley's premier tertiary care institute Sher-i-Kashmir Institute of Medical Sciences (SKIMS) where increasing number of cancer patients especially from the poor backgrounds continue to poor in for treatment. Between Jan to June 2016, over 1500 cancer

patients from the capital city of Srinagar alone were registered for treatment in Regional Cancer Center SKIMS [10]. In Kashmir, esophageal cancer or food pipe cancer in common parlance, is the most predominant cancer present in males as well as females. This cancer by far exceeds the frequency of other cancers in both the sexes contributing about 30% to the total number of cancer cases in Kashmir [11].

Lung cancer ranks next to esophageal cancer in males in the valley. Its association with smoking has been substantiated by innumerable studies, some of which have also established a dose response relationship, in terms of the number of cigarettes smoked per day and the risk of developing lung cancer [12]-[14].

Brain cancer is the third common site of cancer in males in Kashmir accounting for 7% of all cancer cases. This cancer was found to be more common in the male children accounting for 17.4% of total cases in the age group of 0-20 and more than 50% of the cases in the age-group of 0-40 years [11]

Breast cancer, the most frequent cancer of women in the world is the second leading site of cancer in females in Kashmir. Overall in both males and females, it is the second most common cancer present in the Valley. Although the disease is mainly postmenopausal in western population, but the picture in Kashmir is no different than the rest of the country where the burden of breast cancer due to early onset cases is increasing at an alarming rate [11]. As per official records, during 2007-08, the number of cancer patients registered at SMHS hospital, Srinagar was 352, but during 2014-15, the number stood at 3687. In 2015, 4001 new cancer patients were registered in Regional Cancer Center while in 2016, the number of new registrations shot up to 4336. On an average, 15 new cases get registered everyday in SKIMS. The overall figures in the region are most certainly higher due to many unreported cases. Many cancer patients in Kashmir fail to receive immediate healthcare attention due to a lack of awareness and poor health education. An average of 3,000 cancer patients afflicted with various malignancies visit SKIMS every year and the number seems to be increasing day by day.

In a major health concern, the occurrence of breast cancer among women in Kashmir has risen considerably over the years. With its incidence showing an increasing tendency over the last couple of decades, breast cancer has emerged as a major concern among the female population of the Kashmir Valley. However there is no actual database available, yet preliminary indications point towards a rise. Officials at the Oncology Department of SKIMS and Shri Maharaja Hari Singh hospital (SMHS) say that on an average 1-2 patients suffering from breast cancer alone come for the treatment every single day. Among Kashmiri women breast cancer is the second leading cancer after esophageal cancer, with an incidence rate of 12.6 per 100,000. Women in Kashmir are generally diagnosed at a later, more advanced stage with poor prognosis [15]. In the women population of Valley, the frequency of cervical cancer is very low which is quite contrary to the pattern in rest of the country where cervical cancer is the second leading cancer in females after breast

cancer [16]. Kashmir valley is distinct from rest of India with respect to its geography, climate, dietary habits and culture. More than 90% of the population follows Islam. So the incidence of cervical cancer is very less (just 3%) which can be attributed to the universal practice of circumcision among the majority population.

In Kashmir Valley, esophageal cancer is the most prominent cancer present in males as well as in females contributing about 30% to the total number of cancer cases in Kashmir, followed by lung cancer in males and breast cancer in females [11]. The prevalence of breast cancer is almost the same for urban and rural women in Kashmir, the only difference being, cancer in rural women is diagnosed in much later stages, which is fatal [17].

IV. HIGH MORTALITY: A SOCIO-CULTURAL EXPLANATION

Following socio-cultural factors contribute to the higher fatalities of women suffering from breast cancer in Kashmir.

A. Ignorance

Persons with low educational attainment have greater rates of cancer incidence, lower survival rates and higher mortality rates. The most important factor of higher fatality of breast cancer patients in Kashmir is ignorance. Usually symptoms of one disease are associated with the other disease. Sometimes, symptoms are not disclosed till the disease has reached the incurable magnitude. A study undertaken to find the level of awareness regarding breast cancer among Kashmiri females revealed that the level of awareness regarding this disease was very low [17]. Women in Kashmir are least aware about the symptoms, and prevention or control of breast cancer which becomes the major reason of the disease acquiring enormous magnitude.

B. Stigma

Breast cancer is one the most stigmatized cancers all over the world. It is because of the fact that it involves that part of a woman which is least discussed in public. This stigma presents significant challenges to control it. In addition to the lack of awareness, misinformation, poverty as the factors behind growing mortality rate of breast cancer patients, stigma is an important sociological explanation behind the growing mortality of women with breast cancer in Kashmir. This factor discourages women from seeking help until it is too late.

Cultural myths and taboos play their due role in strengthening it. There are several reasons that breast cancer is stigmatized. Most people in the Valley perceive cancer to be a fatal disease. Cancer symptoms or body parts affected by the disease can cultivate stigma. Fears about treatment can also fuel stigma.

C. Turmoil

The people in Kashmir are the worst sufferers of the conflict which is going there for the past sixty years. The frequent shut-downs and curfews keep the whole valley caged for weeks and sometimes for months together. The women suffering from this dreaded disease are not able to consult the specialist in time which minimizes their chances of survival. Other than delayed presentation and diagnosis, the treatment in the form of chemotherapy, radiotherapy etc

also gets postponed many times which results in their disease reaching an enormous magnitude and thus negatively impacting the survival years of the affected.

D. Faith Healers

Faith healers are very much dominant in the socio-cultural structure of Kashmir. A good proportion of population especially women, usually relate their diseases to some evil or bad omen and seek assistance from faith healers (*peers* in local parlance). Thus the disease remains there till it reaches an incurable magnitude. At times, they provide such treatments like incense and other toxic treatments which worsen the situation of the patient.

E. Myths and Misinformation

Kashmiri society is deeply rooted in myths and illogical things. What is more pathetic is that a great deal of misinformation is associated with breast cancer in Kashmir which kills the patients even before their death. This misinformation has many forms like breast removal, expenditure on the patient being useless and non-curability of the disease. Cancer is seen as a death penalty for the patient in Kashmir. Some people are misinformed to such an extent that they feel that the disease is communicable and infectious and does not have any cure. This has a very negative impact on the psyche of the already distressed patient. All such myths decrease the survival years of the patient.

F. Shyness

Being very conservative, the women feel shy of sharing their disease with their family members for a long time. They feel very embarrassed even in practicing Breast Self Examination which is the best and easiest method of detection of breast tumors. They usually prefer to be silent than to disclose their disease to their family members at proper time. Sometimes, they share their problem with their peers and friends before consulting a specialist. Being economically dependent on males, they can't even consult some specialist independently. Thus, not disclosing the disease at appropriate time becomes fatal for them.

G. Taboos

Like every other society, Kashmir Valley is also having a set of cultural taboos. These taboos are very similar to Pakistani cultural taboos. It may be attributed to the same socio-cultural and religious values. Future research in Kashmir will need to determine if the cultural taboos found in Pakistan, that breasts are private and something that should be hidden away and not touched or examined by the women themselves or even male health providers [18], also keep Kashmiri women from seeing physicians for breast related concerns [19]

H. Non-availability of Female Oncologists

This is one of the foremost problems of the health sector in the Valley. Almost all the female specialists in the Valley are associated with a few areas like gynecology, pediatrics, and a few are dealing with dermatology. The field of oncology is occupied with male specialists only. Breasts being the centre of femininity and an object of sensual pleasure, the patients suffering from it hesitate in consulting a male specialist.

Further, the family members, particularly males do not let their women folk examined by a male doctor for detection or treatment of breast tumors. This also delays the treatment and hence the survival of the patients is at risk. Further many non oncology medical professionals like General Surgeons, Gynecologists etc tend to treat breast cancer themselves leading to incorrect decisions, unwanted investigations and inadequate surgeries and this directly affects the outcome and longevity of the patient.

I. Late Presentation

In Kashmir, breast cancer is a non-existent entity for a majority of population till a near and dear one suffers from it. Healthcare is low on priority and even in major towns screening is an 'alien' word for most people. So naturally, this results in most people presenting only when symptomatic, and on an average, most 'symptomatic' cancers are stage 2B and beyond. So the breast cancer patients in Kashmir do not tend to survive for a longer time.

Further, women in Kashmir are less concerned about their general health. The health of male folk and children is their priority. Avoidance of the disease, shyness, ignorance, poverty, and the frequent curfews and strikes results in the late presentation of breast cancer before an oncologist. Experts say that delays in the curative treatment escalate deaths as it gives rise to the late detection of the disease among the patients.

V. RECOMMENDATIONS

A. Education

Ignorance being the primary factor behind the growing number of fatalities in rural areas, education can go a long way in controlling this disease. In this connection, media can play its role in dissemination of breast health education. A high proportion of women regularly viewed television (84%) and listened to local radio (80%) in Kashmir Valley according to a study [20]. Therefore, media-based interventions can help in the efforts to enhance awareness or promote screening. Further, this breast health education should be inclusive ie, it should include the patients as well as the healthy women so that more and more information will be disseminated to maximum population in rural areas and the myths and stigma attached with breast cancer will no longer persist.

The school system represents a potential venue for cancer education, and increasing cancer awareness among children may be an investment with high returns. Cancer education especially breast cancer education should be included in the curriculum in schools so that more and more awareness gets disseminated in the society.

B. Female expertise needed

Due to a strong grip of traditions, females in rural Kashmir feel shy and hesitant of getting examined by a male doctor. So there is a strong need of female oncologists. There is an increasing trend of females opting for pediatrics, gynecology or dermatology in Kashmir. The need of the hour is that more and more females excel in critical fields of oncology especially breast cancer. The unaware and shy women of

Kashmir need female specialists for treating breast tumors at appropriate time. This will definitely impact the survival years of the patients.

C. Organization of awareness camps

If you have read all the above points, they are all pointing to one necessity - screening for breast cancer. Since the number of cases is rising, younger women are getting affected, most are presenting only after symptoms develop (so usually stage 2B and beyond, rarely earlier stage) and we cannot prevent this cancer, all we can do is to detect this cancer early. Screening is the way to go. In Kashmir valley, dedicated breast cancer screening clinics are nonexistent and hence increased breast cancer awareness among general population can be a hope to fight this disease. Many of the myths associated with breast cancer among people in rural Kashmir like breast cancer being infectious, non-treatable and non-curable, and the fear of breast removal can be removed. Awareness camps by female experts about BSE in remote areas will also help in early detection of the disease and hence decreasing the mortality rate of patients. Mobile mammography clinics can also play an important role in this process. As already stated, rural women share their problem with their peers, so mass education related to breast health and cancer will be an important initiative in creating a positive mind-set regarding breast cancer in rural areas.

D. Role of Non Government Organizations

There are a lot of NGO's working on different fronts in Kashmir. But when it comes to cancer, there is a virtual silence from them. Presently, very few NGO's are working actively in terms of cancer awareness, screening, detection and treatment. The Cancer Society of Kashmir is one such example which is wholly funded by the philanthropist business community and bureaucrats of Kashmir and outside. This Society is meant for those affected who are living below poverty line who could not afford the timely treatment. But one organization can't carry the burden of all the poor patients. So there is a need of more and more organizations for poor cancer patients. Further these organizations need to be funded adequately.

E. Resolution of the conflict

Finally, the state government of Jammu and Kashmir, Union Government of India and the international bodies should make sincere efforts to resolve the burning issue of Kashmir without any delay because the worst sufferers of this turmoil are the women folk and their health for no fault of theirs. This will also serve in introducing new innovations and technologies in the field of oncology. Top specialists of the Valley can return to their homeland and there won't be any dearth of expertise.

F. Communication

Communication is critical to decreasing cancer-related stigma, raising cancer awareness, and disseminating cancer education. People with a personal history of cancer—especially well-known or celebrity survivors—and multiple mass media channels are key resources for dissemination (Daher, 2012). Kashmir too needs well developed communication system in terms of mass media to disseminate the breast health education.

VI. CONCLUSION

There is possibly no way to prevent breast cancer as it can happen to any woman irrespective of her class, color and religion. But we can definitely detect it early and treat adequately. Longer survival can be expected only and only with early detection. The organization of health programs for women at grassroots level that include breast health, can serve as feasible options for research and education on earlier detection of, and eventually, screening of women for breast cancer in underdeveloped regions including Kashmir Valley. Since Kashmir already has worst survivals from breast cancer, organization of early detection and screening programs in remote areas of the Valley is the immediate need of the hour. In order to impact the survival of the breast cancer patients, an economically viable diagnostic facility such as mammography would need to be implemented in rural and remote areas. Finally, the political and social conflicts in the region must be minimized in order to ensure safe and timely diagnosis and treatment of breast cancer patients in the Valley.

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Mehnaz Hassan has quite recently submitted her Ph.D thesis in the Department of Sociology, University of Kashmir on Gender and Health. She has several publications on women's issues, particularly health. She has also contributed in NME-ICT e-contents sponsored by Ministry of Human Resource Development, Govt of India for undergraduate courses. She has presented her research work in several international and national conferences including Women's World Congress, Hyderabad and Indian Sociological Conferences each in Varanasi, Bhubaneshwar, Patna and Lucknow.