COMMENTARY

Breast Cancer in Malaysia : Are Our Women Getting The Right Message? 10 Year-Experience in A Single Institution In Malaysia

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Abstract

The message that health care providers caring for patients with breast cancer would like to put forth, is that, not only early detection is crucial but early treatment too is important in ensuring survival. This paper examines the pattern of presentation at a single institution over a 10-year period from 1995 to 2005. In Malaysia, education outreach programmes are ongoing, with contributions not only from the public sector, but also private enterprise. Articles on breast cancer in local newspapers and women magazines and television are quite commonplace. However are our women getting the right message? Now is an appropriate time to bring the stakeholders together to formulate a way to reach all women in Malaysia, not excluding the fact that we are from different races, different education levels and backgrounds requiring differing ways of delivering health promotion messages. To answer the question of why women present late, we prospectively studied 25 women who presented with locally advanced disease. A quantitative, quasi-qualitative study was embarked upon, as a prelude to a more detailed study. Reasons for presenting late were recorded. We also looked at the pattern of presentation of breast lumps in women to our breast clinic in UMMC and in the surgical clinic in Hospital Kota Bharu, in the smaller capital of the state of Kelantan, in 2003. There is hope for the future, the government being a socially responsible one is currently making efforts towards mammographic screening in Malaysia. However understanding of the disease, acceptance of medical treatment and providing resources is imperative to ensure that health behaviour exhibited by our women is not self-destructive but self-preserving. Women are an integral part of not only the nation's workforce but the lifeline of the family - hopefully in the next decade we will see great improvement in the survival of Malaysian women with breast cancer.

Key Words: Breast cancer survival - early detection - late presentation - health messages

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Introduction

The age-specific incidence of breast cancer in Malaysia is much lower than in the western world. The second report of the Malaysian National Cancer Registry in 2004 alluded that 46.2 in 100,000 population was diagnosed with breast cancer in 2003 (Lim and Halimah, 2004) this is compared to 130 in 100,000 population in the United States. Despite a low incidence as compared to other countries, breast cancer is the commonest cancer amongst Malaysian women, where breast cancer made up 31% of women diagnosed with cancer that year. Breast cancer is more common amongst Chinese and Indian women compared to Malay women in Malaysia. Although the incidence is low, breast cancer in Malaysia could be considered as the leading cause of cancer death among women. It is very discouraging to know that there is a discrepancy in survival in Malaysia as compared to developed nations. The 5-year relative survival rates in the United States in 2000 approached 90%. In Malaysia there are no national survival data. In UMMC the 5-year survival rate for patients diagnosed from 1993 to 1997 was only 58.4% (CI 0.538-0.634) (Yip et al.,2006). Racial discrepancy in the 5-year survival was seen among the three major ethnic groups, with Malay women surviving only 46%, Chinese women, 63% and Indian women having a 57% 5-year survival rate. Reasons behind this discrepancy could be due to differing screening practices, health seeking behaviour, treatment compliance and health resources available to Malaysian women.

We would like to examine whether our women have received the right message to be able to survive breast cancer. The important message health care providers caring for patients with breast cancer would like to put forth is that, not only early detection is imperative but also early treatment. As we know survival of patients with

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breast cancer is dependant on the stage when the patients receive treatment. This paper will look into the pattern of presentation, the pattern of women presenting to breast clinics when they find a lump. We will also discuss the findings of a study that examines women presentingwith advanced disease. A preliminary report of findings of a study on breast cancer screening practices amongst Klang Valley general practitioners is also included.

10-year Audit of Breast Cancer Patients in UMMC

In UMMC over a period of 10 years, we saw an increase in new cases of breast cancer, in 1995 we saw 83 patients, in 2000, 154 and in 2005, 340 newly diagnosed patients. Although we saw a rise in new cases diagnosed with breast cancer, the rise in the numbers of women diagnosed with breast cancer in our centre could be attributed to the maturing of the breast services in the hospital and not to due to a rising trend in the incidence of breast cancer. In the 10-year review, we did not see much improvement in the stage of the cancer at presentation. We also saw that there was no improvement in size of tumour at presentation. The pattern that was seen was very discouraging with Malay women presenting with the largest tumour size, the mean size in 1995 was 6.57 cm (SD 6.242) and in 2005 was 5.05cm (SD 5.296) Chinese women did show some improvement, where in 1995 the tumour size was 4.23cm (SD3.635) and in 2005, 3.64 cm(SD 3.052) The tumour size for Indian women in 1995 was 2.99cm (SD 1.073) in 2005, 3.71 cm (SD2.492). The overall mean size in 2005 was 3.95 cm (SD 3.671) slightly smaller as compared to 4.39cm (SD 3.791) in 1995. In Hospital Kuala Lumpur (HKL) between 1998 to 2001 the average size of the tumour was 5.4 cm in diameter, during the same time, the average tumour size in UMMC was 4.2 cm (Hisham and Yip, 2004).

The reason why women present at an earlier stage in UMMC, could be due to the fact that UMMC sees more Chinese patients compared to HKL. The mean size of tumour in UMMC in 2005 although smaller, still remained above 2 cm. In order to reduce breast lump size from to 2 cm to 1 cm or less, population-based mammographic screening is needed. Reducing tumour size from 5 cm to 2 cm is still warranted in our setting, as the mean size in our hospital population is about 4cm, this may be achieved through breast self examination and clinical breast examination. There must also be willingness of the patients to undergo treatment at an earlier stage. The stage of cancer remained almost similar, spanning over 10 years, with most women being in stage 2, where the percentage was 51.8%, 53.9%, and 52.4% for 1995, 2000 and 2005. Advanced disease like stage 3 for the 1995, 2000 and 2005 were 15.6%, 11%, 14.7%, and stage 4 was 6%, 10.4% and 7.6%. Very early breast cancer i.e. Stage 1 was 26.6%, 24.7% and 25.3%. Therefore in view of the small change in size of tumour, and no difference in the pattern according to stage of disease there would be no or minimal impact in the survival of patients in our hospital in the next 5 years. Efforts to reduce the average breast lump size from 4 cm to 2 cm should be carried out by means of breast self examination. Although the current evidence show that teaching BSE did not improve survival in the large randomized study in Shanghai involving 266 000 women with about 10-11 years follow-up (Thomas et al.,2002). However it must be taken into account that the population of women studied were very breast aware, the overall survival in both arms were above 90%. It was seen that even in the control arm, 44.8% of the women found breast lumps 2 cm or smaller, almost similar to the group who were taught BSE (48.8%). Therefore in Malaysia, there is still room for the use of BSE to create breast awareness, hopefully in years to come, our women will present with average breast lump size of 2 cm.

Large randomized trials on clinical breast examination have not been carried out, however a very important study was conducted in the Philippines (Pisani et al.,2006)This study was an epidemiological study employing trained nurses for population-based clinical breast examination screening. It showed a refractory attitude of the population with respect to clinical follow-up i.e. despite detecting breast lumps, the women refused further investigations, Initially 92% of women accepted the invitation, but of the positively detected women, only 35% completed diagnostic follow-up. In our country, this health behaviour may be similar, therefore studies should be carried out by psycho-sociologists to look into this peculiarity and to find ways to improve health promotion in this group of people. Finding smaller lumps may not translate to better survival as women still have problems accepting conventional hospital treatment. Therefore we have to understand the health behaviour of our population before employing any mode of screening.

Breast Clinics in Malaysia

In investigating the availability of breast health services, the pattern of women presenting with a breast lump in two breast clinics were studied over a period of one month in 2003 by medical students undergoing their electives in UMMC and in Hospital Kota Bharu. In UMMC, 103 new patients with breast lumps presented to the breast clinic. 48.5% were less than 30 years old. 86.4% of them discovered their breast lump on their own. 64.1% were referred. 63.1% presented within two weeks of discovery. Only 11.2% waited for more than four weeks. Only 5.9% said that they were afraid and felt embarrassed to see a doctor. 54.4% of the patients thought their breast lump was benign, followed by 28.2% who were undecided and 17.5% thought their breast lump may be malignant. Only 57.3% of the patients actually knew how to perform Breast Self Examination correctly and only 52.4% practiced breast self- examination at home. Majority of them (59.2%) failed to know the main purpose of screening mammogram.15.5% sought traditional treatment before attending the breast clinic.

Factors that were found to be associated with delay (More than 2 weeks of presentation) were the age of patients, marital status, number of children and place of residence. It was found that only 69.9% of the patients actually had a clinically palpable breast lump and 29.1% had normal breasts. The final outcome of the lumps that

were investigated was that only 4.9% was confirmed malignant. In Hospital Kota Bharu, 75 patients were studied in the same period of time. 53.3% of the women were more than 40 years old and 38.7% were between 40 to 49 years old. 48% of them were housewives. 94.7% found the breast lump themselves. 62.7% were referred by a GP, 22.7% were influenced by a friend or relative. Only 14.7% came on their own. Only 24% presented to a GP within 2 weeks and 76% presented after more than 2 weeks. In contrast, 25% of patients in Kuala Lumpur presented within 8 weeks, 16% after more than 12 weeks and 18.7% after more than 11 months. Some 73.3% referred by GPs were seen within 2 weeks. In contrast with women in UMMC, 45.3% sought traditional treatment before coming to hospital. The outcome of the patients seen in Kota Bharu, was that 26.7% of the patients had cancerous breast lumps. The only factor that was found to be significant in delaying the presentation to hospital was the women's attribution whether the lump was cancerous or non-cancerous (p= 0.035) Other factors like age, place of residence, level of education and marital status did not significantly affect the delay at presentation. The differing patterns that were seen between the two hospitals, reflected the two differing populations studied. More women presenting to HKB delay their presentation to the GP. The women that were seen in UMMC were younger. More women presenting to HKB use traditional medicine - 45.3% vs 15.5%. The pick up rate for breast cancer were higher in HKB: 26.7% compared to 4.9% in UMMC. More women with benign conditions of the breasts present to the UMMC breast clinic. This reflects a higher degree of breast awareness and acceptance to hospital treatment. Factors which affected the delay in presentation in UMMC, were mainly reasons affected by convenience of the examination like the place of residence, the number of children and age of patient and the marital status of the patients rather than to whether they attributed the lump was cancerous or not as was seen amongst the patients in Hospital Kota Bharu. This small study shows that there are breast clinics available in the country and that patients can be seen early, within 2 weeks of referral from GPs.†Convenience is a major factor in helping women attend to their health affairs,as they often have to care for their children and not able to attend clinics.

Surprisingly shyness towards doctors is not a major issue in this group of women studied.†A woman,Äôs fear that she will be diagnosed with cancer is a factor that can delay their presentation. We saw from this study that women attending breast clinic in Kelantan was more likely to delay presenting to the hospital; compared to women in Kuala Lumpur. This may reflect some of the coping mechanisms that our women have when faced with the fear of being diagnosed with breast cancer. The effect of this attitude, delays diagnosis and treatment. This in turn dangerously affects cure of a potentially curable disease. We also saw the inefficiency of BSE as only half the women attending UMMC were correctly doing BSE. Many did not know the main purpose of a screening mammogram. Therefore there is room for improvement in educating the public. The health messages are still not getting through.

Why do Women Present Late?

We prospectively looked at 25 women who presented with locally advanced and/or metastatic disease. A quantitative, quasi-qualitative study was embarked upon, as a prelude to a more detailed study. Reasons for presenting late were recorded. We studied 25 patients diagnosed with stage 3 and 4 cancer seen in the surgical and oncology services in UMMC between Dec 2002 and Jan 2003. Physician directed questionnaire was used using close and open ended questions.Demography, alternative therapy practices, reasons for delayed presentation and reasons that would make them present sooner were studied. The mean age was 45.8 years (range 30-74). 13 of the patients were Chinese, 12 were Malay, 1 Indian and 1 patient was an Indonesian. Two were not working, nine were homemakers, five were clerks, one was a kindergarten teacher, one a headmistress, one was an accounts officer, one tailor, one domestic maid,†onewas a homemaker cum school van driver, two were not recorded. 64% had more than three children. 16% were nulliparous. 13 stayed in a town, one was from the city and four from the rural area. 84% were married, 4% were divorced, 12% were single. 76% lived with their husband and children. Only one lived alone. 68% of the patients claim that they knew about breast cancer. The source of breast cancer information was mainly from the media 73%, from friends 20%, public health talks (klinik desa) 4%. Most of the women found the lumps themselves, one was detected on screening mammogram, two were not sure. Nine patients had previous exposure to family members or friends with breast cancer, 3 had mothers or sisters with breast cancer. Fatalistic view of cancer may be a reason for women not wanting to have treatment, as their only role models may nave succumbed to the disease, better role models in breast cancer survivors may be a good way to remove the fear in these women6. Four women took more than one year to tell somebody about the breast lump. One patient took three 3 years. Duration of breast lumps ranged from 2 months to 60 months. One lady had found the cancer on hook wire localization biopsy after a screening mammogram, but did not have treatment until the disease was at stage 3, 5 years later. As mentioned before, we have to understand and hopefully find ways of altering their health behaviour to achieve better survival for our patients with breast cancer.

Most of the women sought some form of treatment within 2 months after discovering the lump. Most of them consulted a doctor first. Surprisingly, only three consulted alternative practitioners first. One patient consulted five doctors. Most patients consulted specialists. 60% of the women studied used alternative therapy. The types of alternative therapy that were used were oral preparations, applications and spiritual prayers. Four patients did not pay anything for the alternative treatment. Eight of the fifteen women who responded to this question paid more than RM 1 000.00 (approximately USD 300) and one paid RM 20 000.00 and another paid RM 40 000.00. The numerous reasons for using alternative therapy were: fear of surgery, influenced by friends, thought that alternative therapy works, previous bad experience in hospital,

financial problems, was afraid that she cannot work after the mastectomy, no time, have young children, prayer was sufficient, thought it wasn,Äôt cancer and was shy to see doctor. The reasons for finally coming to hospital were: all else failed where the lump was enlarging and when they realized the treatment that they were on was not working. Some had pain, some had ulcerating or bleeding tumours, three were forced by others; one patient had her very large breast lump discovered by doctors under general anaesthesia, as she was a renal transplant donor, she was donating her kidney to her husband, the transplant was then cancelled, one fainted and the tumour was discovered by the examining doctor, and one was brought to hospital by her children when the children found out about the lump, one lady was unfortunate as she presented with a small lump but had already metastasis and one had abdominal distension from progressive cancer.

Role of Primary Care Physicians

Early detection and treatment of breast cancer could be enhanced at the primary care level with the help of general practitioners (GPs), therefore a study on the breast cancer screening practices among general practitioners in the Klang Valley was conducted with collaboration with the Department of Primary Care and Department of Social and Preventive Medicine University Of Malaya. Postal questionnaires to general practitioners registered with the Malaysian Medical Council were sent out in May 2006. 700 GPs were invited to participate, there were 269 respondents giving a response rate of 38.4%. Preliminary results of this study were reported. Only 58.7% of the respondents claim that they screen symptomatic women for breast cancer. Among those who practice screening, 98.6% would teach Breast Self Examination techniques, 97.3% does Clinical Breast Examination. 87.1% would order screening mammogram. Only 54% knew breast cancer is the commonest cancer among Malaysian women and only 54% of GPs knew that the prevalent age group was 40-49 years old. Among women seen in their clinic, the GPs agreed that 49% found that few women would initiate breast screening discussions, 36% agreed that some women intiate discussions.

The top three reasons why the GPs do not perform mammographic screening were; patients do not come for routine health examinations, patient cannot afford mammogram and another doctor would have already ordered the mammogram. The main reasons why Clinical Breast Examination (CBE) was not performed were; patients do not come for routine health examination, mammogram is more sensitive than CBE and the patient,Äôs culture and religion is a barrier. Only 27.2% of the GPs were aware of the Clinical Practice Guidelines (MOH, 2002), only 33 or 45.2% have read the guidelines but only 18 found it useful. In conclusion, breast cancer screening practice amongst the GPs in the Klang Valley was still below expectations. Improvement in education on cancer prevention should be a priority in our country, guidelines specifically for GPs providing preventative health care should be considered. The public should be encouraged to practice preventive health, subsidy for mammography screening should be considered and incentives to GPs practicing preventive medicine should be in place. To adopt population-based screening may not be cost effective as breast cancer incidence remains low in Malaysia. However one must not forget that treatment of advanced cancer is of very high cost therefore opportunistic screening should be encouraged especially in high risk groups.

In Malaysia, education outreach programmes had been ongoing. Contributions are not only from the public sector, but the private sector too. Articles on breast cancer in local newspapers and women magazines and television are quite commonplace. However are our women getting the right message? From this brief overview of a single institution in the Klang Valley, we are still not getting the message across. It is an appropriate time to bring stakeholders together to formulate a way to reach all women in Malaysia, recognizing differences in races, education levels and backgrounds thus having differing ways of receiving and responding to health messages.

In January 2005, the Breast health Global Initiative (BHGI) Breast Cancer in Limited Resource Countries: Early Detection and Access to Care Panel reaffirmed the core principal that a requirement at all resource levels is that women should be supported in seeking care and should have access to appropriate, affordable diagnostic tests and treatment. Breast health awareness should be promoted to all women, effective training of relevant staff in CBE both for symptomatic and asymptomatic women and opportunistic screening with CBE should be promoted. Trials on organized screening using CBE or BSE and feasibility studies on mammographic screening should be promoted (Smith et al. 2006). There is hope for the future, the Malaysian government being a socially responsible one is currently making efforts towards population-based mammographic screening in Malaysia, with a pilot project underway. However understanding of the natural history of the disease, acceptance of medical treatment and availability of resources is imperative in ensuring that health behaviour exhibited by our women is not self-destructive but self-preserving. One cannot deny that a woman is an integral part of not only the nation's workforce but the lifeline of the family - hopefully in the next decade we will see great improvement in the survival of Malaysian women with breast cancer.

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