

Exploring the Economic Impact on Breast Cancer Patients in Kelantan

Impak Ekonomi kepada Pesakit Kanser Payudara di Kelantan

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Abstract

Breast cancer is the most common form of cancer and accounts for more than 30% of newly diagnosed cancer cases in Malaysian women. In 2006, the National Cancer Registry recorded 3525 cases of female breast cancer in Peninsular Malaysia. The economic impact of breast cancer is double pronged with families not only losing household income but also incurring greater expenses. This study examined the economic impact on breast cancer patients in Kelantan, Malaysia and involved 40 respondents. Data were collected using guided interviews. Our study showed that all the respondents who were working prior to the diagnosis of this illness were adversely affected. The most seriously affected ones were those who had to stop work and lost 100% of their income. Another group of patients suffered pay cuts because they had to limit their working hours or opted to work part-time. Most of the adversely affected cases were from the lower income groups and were mainly self-employed. The financial burden resulting from mainly non-medical expenses as well as the income loss has pushed some of the respondents into financial difficulties. Some of them used up their savings, borrowed and delayed their payments for essential services such as telephone, water, electricity, rental or loans. For respondents from the lower income group, the loss of income may result in falling into poverty, a process that has been referred to as 'the medical poverty trap'.

Keywords economic impact, breast cancer patients, Kelantan

Abstrak

Kanser payudara adalah penyakit yang paling kerap berlaku dalam kalangan wanita di negara ini yang merangkumi lebih daripada 30% kes kanser yang baru didiagnosis di kalangan wanita Malaysia. Pada tahun 2006, Pendaftaran Kanser Nasional mencatatkan 3525 kes kanser payudara dalam kalangan wanita di Semenanjung Malaysia. Kesan ekonomi kanser payudara diibaratkan seperti 'sudah jatuh ditimpa tangga', keluarga bukan sahaja kehilangan pendapatan isi rumah tetapi juga terpaksa menanggung perbelanjaan yang lebih besar. Kajian ini mengkaji kesan ekonomi di atas pesakit kanser payudara di Kelantan, Malaysia dan melibatkan 40 orang responden. Data dikumpul dengan menggunakan temubual berpandu. Kajian menunjukkan bahawa semua responden yang telah bekerja sebelum diagnosis penyakit ini telah terjejas. Pesakit yang paling serius terjejas adalah yang terpaksa berhenti kerja dan hilang 100% daripada pendapatan mereka. Satu lagi kumpulan pesakit mengalami pemotongan gaji kerana mereka terpaksa menghadkan waktu kerja mereka atau memilih untuk bekerja sambil. Kebanyakan kes yang terjejas teruk adalah dari golongan berpendapatan rendah dan bekerja sendiri. Bebanan dan masalah kewangan disebabkan oleh perbelanjaan lain daripada perubatan dan kehilangan pendapatan. Sebahagian daripada mereka terpaksa mengguna simpanan mereka, meminjam dan menanggung bayaran untuk perkhidmatan asas seperti telefon, air, elektrik, sewa atau pinjaman. Bagi responden dari kumpulan berpendapatan rendah, kehilangan pendapatan boleh menyebabkan mereka termasuk dalam kategori "miskin" dan keadaan ini lazimnya dirujuk sebagai 'perangkap kemiskinan perubatan'.

Kata Kunci kesan ekonomi, pesakit kanser payudara, Kelantan

Introduction

Breast cancer is a major cause of death and the most common cancer among Malaysian women. It accounts for more than 30% of newly diagnosed cancer cases in Malaysian women. In 2006, the National Cancer Registry recorded 3525 cases of female breast cancer in Peninsular Malaysia. Based on the National Cancer Registry of Malaysia data, the age-standardized incidence rate (ASR) was

46.2 per 100,000 women in 2004. However, the rate differs between the three main races, the Malays, Chinese and Indians. The age-standardized incidence was highest between the Chinese, with 59.7 per 100,000, followed by the Indians at 55.8 per 100,000 while the Malays had the lowest incidence of 33.9 per 100,000. This translated into 1 in 16 Chinese, 1 in 16 Indian and 1 in 28 Malay women developing breast cancer at some stage in their lives. In many developed nations, the disease is prevalent among older women, but in Malaysia, 52.3% of the cases of breast cancer involved women below 50 years of age with the most common age group affected between 40-49 years (Yip *et al.* 2006).

Kelantan had a population size of about 1.5 million in year 2010 where 95.7% were Malays, 3.4% were Chinese, 0.3% were Indians and 0.6% from other ethnic groups. The state Cancer Registry Report (1999-2003) shows that the most common cancer among Kelantan's women was breast cancer with 370 cases (ASR 13.9) (Kelantan Registry Report No. 1, 2006). The Chinese (ASR 37.0) had the highest incidence followed by the Indian (ASR 34.5) and the Malays (ASR 12.5). The youngest age of breast cancer case was 19 years old and the peak age group was between 50-54 years old.

Those most affected by the disease are the women themselves, the family structure, and their children. Cancer, as with many chronic diseases that need prolonged treatment regimens, will have impact on the patients' economic status. The economic stability of the family is an issue because many women in Malaysia work. Women with breast cancer can foster economic problems in the wider community, as many of these women cannot work during treatment, are not able to return to the work force even if they survive, and there was a high probability of morbidity and mortality.

The economic impact of breast cancer is actually a double pronged with families losing household income as well as having to face greater expenses. There are several reasons why understanding the economic impact of breast cancer on patients and their families is important. First, the financial burden may contribute to patients' decisions about treatment and recovery. Second, treatment processes may affect women's ability to continue to work, job loss and income loss. Prolonged primary and adjuvant treatment for breast cancer may cause further disruption to workplace activities and earnings. Third, for patients from the lower income group, loss of income may result in falling into poverty, a process that has been referred to as "the medical poverty trap" (Whitehead *et al.* 2001).

A study on Canadian women diagnosed with early breast cancer, found that on average they lost more than a quarter of their typical income during the first 12 months after their diagnosis (Maunsell, 2009). Those who were more likely to suffer large wage losses were less educated, lived farther from the hospital where they underwent treatment, had more serious disease, had less social support, required chemotherapy, or were self-employed, and worked part-time or were recently hired at their current job. In Australia, the main economic impact on individuals with breast cancer was loss of income followed by out-of-pocket costs for health services (Gordon *et al.*, 2007). This study also indicated that younger women (less than 50 years old) were more vulnerable in terms of large economic burden after breast cancer diagnosis. In the United States, older patients have to face significant out-of-pocket expenses particularly for medications and home services (Moore, 1999). Hensley *et al.* (2005) described the negative impact of breast cancer on employment and the denial of life insurance to breast cancer patients in the US. Grunfeld *et al.* (2004) carried out a study on the impact on caregivers of breast cancer patients in Canada. Their studies showed that 69% of the employed caregivers reported some form of adverse impact on work.

In Malaysia most studies concentrated on the clinical aspects of the disease but not the economic burden on the patient. The first economic impact study on cancer patients was launched by The Public Health Medicine Specialist Association of Malaysia (MPHSA) on the economic burden of Human Papillomavirus (HPV) infections and cervical cancer in Malaysia in early 2009 (*The Star Newspaper*, 5 April 2009). The team was responsible for developing an economic model encompassing the costs of cervical cancer disease attributable to HPV infection, and to conduct a health economic study on HPV vaccination in Malaysia. It is crucial for us to gather local data on breast cancer to determine the burden of breast cancer illness, as it is the most common cancer-affecting women in Malaysia. Understanding the economic impact may help those diagnosed with breast cancer plan for anticipated costs and enable health professionals to identify women who may benefit from support programs.

Objective and Methodology

The aim of this paper is to look at the economic impact of breast cancer on the patients in Kelantan. We assessed the reported expenses and the source of financial aids that they had obtained. We measured the impact of the illness from a few aspects such as employment, income, savings and household budget.

Participants were purposively sourced from the main hospital with oncology services in Kelantan. 40 respondents were purposively selected among female breast cancer patients seeking treatment at the Nuclear Medicine Clinic, Universiti Sains Malaysia Hospital between March and July 2009. The inclusion criteria were confirmed breast cancer cases, and female Malaysians aged 21 and above. Ethics approval was obtained on 28th October 2008 from the Research Ethics Committee (Human), Universiti Sains Malaysia. Explanation regarding the content in the patient information sheet was given to the respondents. Before taking part, respondents were required to sign the consent forms.

A locally trained enumerator using a pretested interviewer guided questionnaire collected the data. Before the interviews took place, the research objectives were explained to the respondents and their consents were taken. The respondents were allowed to further elaborate on any questions when necessary. All interviews were tape recorded and were transcribed verbatim. Both quantitative and qualitative data from the questionnaire and transcripts were analyzed simultaneously.

The guided questionnaire comprised of two main parts. The first part explored the socio-economic background of the respondents and included information related to the diagnoses of cancer. The second part focused on the economic impact of the cancer since the diagnosis; work related issues, treatment expenses and household expenses were discussed.

Patients Profile

40 breast cancer patients were involved in this study. The age of respondents ranged from 19 to 61 years with a mean of 51.8 (SD 8.56) years. Eighty two percent of them were Malays and 85% of them were married. About 48% of them had their highest formal education up until upper secondary (forms four to six) and only 12.5% of them were degree holders. The details of the race, highest education level and marital status are as presented in table 1.

The number of children (including stepchildren and adopted) of the respondents was between 0 and 9, but most (22.5%) had four children. However, further review of the qualitative data suggested that the number of children who were still financially dependent on the family was between one and three. About 40.0% of the respondents also reported having at least one other dependent whom they provide financial assistance to, either on a regular or non-regular basis. These dependents could be the mothers, younger siblings or nieces and nephews of the respondents.

With regard to employment, the largest group worked in the public sector, followed by those who were not working, self-employed or working in the private sector. Many of those working with the government were either teachers or nurses. Most of the self-employed were minor traders. The monthly family income ranged (n=31) from RM120.00 to RM12, 000.00, however the distribution was skewed to the right with the median value of RM2, 700.00 (IQR RM 3,750.00). Further qualitative analysis revealed that both the husband and wife, or the husband alone either contributed most of the family income jointly. The qualitative data also indicated that the husbands were either working in the public sector (presently or previously before retirement), private sector, self-employed, or in isolated cases, unemployed. However, a more comprehensive analysis on spouse's occupation is not feasible as not all the respondents voluntarily offered this information. On the other hand, the monthly personal income (n=25) which ranged from RM 120.00 to RM 6,000.00 was relatively normally distributed with a median of RM 2000.00 (IQR RM2000.00). Table 2 shows the employment sectors of the respondents as well as the monthly family income and individual income.

The year in which the respondents were diagnosed with breast cancer ranged from 1999 to 2009 as shown in Table 3. However, the highest percentage was year 2008 (37.5%). Most of the subjects were diagnosed at stage 2 (40.0%), while 15.0% were diagnosed at stage 1, 12.5% stage at 3, 17.5% at stage 4 and the rest (15.0%) were not sure. An American study reported a range of between 0% to 50% of cancer survivors [from different ethnicities] not knowing their stage of disease at

diagnosis (Ashing-Giwa *et al.*, 2004), therefore, this finding appears to be consistent. Among the reasons obtained from the qualitative data for being, unsure included not seeking this information from the doctor or that different doctors gave them conflicting information. Some of those who were unsure of the cancer stage at diagnosis claimed that the doctor did not inform them about it and one respondent reported specifically asking the doctor and not getting an answer.

Table 1 Racial distribution and the education levels of the respondents ($n = 40$)

Variable	Frequency (%)
Race	
Malay	33 (82.5)
Chinese	6 (15.0)
Others	1 (2.5)
Highest education attained	
Unschooling	2 (5.0)
Primary schooling	8 (20.0)
Lower secondary schooling (Form 1-3)	2 (5.0)
Upper secondary schooling (Form 4-6)	19 (47.5)
Diploma	4 (10.0)
Degree	5 (12.5)
Marital status	
Single	3 (7.5)
Married	34 (85.0)
Widowed	1 (2.5)
Divorced	2 (5.0)

Table 2 Employment sector and monthly income of study sample ($n = 40$)

Variable	Mean (SD)	Median (IQR)	Frequency (%)
Employment sector			
Public			14 (35.0)
Private			4 (10.0)
Self-employed			10 (25.0)
Not working			12 (30.0)
Personal monthly income (RM) (n=25)	2,309.20 (1664.16)	2000.00 (2000.00)	
Family monthly income (RM) (n=31)	3012.25 (2908.00)	2700.00 (3750.00)	

SD= Standard deviation, IQR= Interquartile range

Table 3 Cancer stage at diagnosis and year of diagnosis ($n = 40$)

Cancer stage at diagnosis	Year of diagnosis										Total	
	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008		2009
Stage 1	1	0	0	0	0	0	0	0	1	3	1	6
Stage 2	0	0	0	1	0	3	0	0	1	8	3	16
Stage 3	0	0	1	0	0	0	1	0	2	1	0	5
Stage 4	0	1	0	0	1	0	0	0	2	2	1	7
Unsure	0	0	1	0	0	0	1	1	2	1	0	6
Total	1	1	2	1	1	3	2	1	8	15	5	40

Economic Impact

Patient's Expenses

Breast cancer treatment is individualized to the patient and conventional medical treatment expenses comprise of surgery costs that may be either a lump removal or a whole breast removal (mastectomy).

Whereas, chemotherapy costs which would depend on the type of drug regimen and number of cycles of treatment and may include radiotherapy costs, which would depend on the number of cycles and courses, prescribed? Other expenses related to the treatment would be the investigative procedures that the doctor would require to correctly diagnose and stage the patient as well as the related medications to manage the various side effects of treatment. Estimates of the charges that may be incurred are shown in Table 4. It has been reported that surgery, chemotherapy (using standard drugs) and radiotherapy costs in the private hospital is around RM20,000.00 to RM30,000.00 (*The Star Newspaper*, 29 June 2008). An anecdotal report on the cost of chemotherapy (not standard regimen) and other supportive medications received in a Government Hospital was RM 77 400.00. Fortunately, in this case, the employer (W.M Kamil, personal communication, 3 July 2009) covered the cost of treatment.

All the patients had been receiving treatment from a Government Hospital, which meant that all were receiving subsidized treatment. When asked about the total amount spent by them on the treatment for their condition, 81.1% said that they did not have to pay anything, and almost all the amount that was reported as medical expenses by the patients is lower than the costs of medical treatment that have been estimated in table 4. The percentages of respondents who reported spending on surgery, radiotherapy and chemotherapy were 5.9%, 7.7% and 8.3% respectively. Table 5 shows that almost all (97%) reported non-medical monthly expenses related to the disease and almost half (43.6%) had spent on traditional/complimentary medicine.

However, a study in Canada found that despite having a public health care system that covers the treatment and hospital-related costs, some patients particularly those who received two and three different types of adjuvant treatments, lived far from the hospital, had higher education and were working at diagnosis were still at risk of experiencing financial burden due to higher out of pocket costs (Lauzier *et al.*, 2013).

Surgery

There was no response from six patients and the others reported no surgical expenses even though all 40 respondents had undergone surgery. On qualitative analysis, however, two respondents described some payment for surgery; one had her initial surgery in a private hospital outside Kelantan even though she was eligible for free treatment as a government employee because she felt that the waiting time for an appointment would be shorter. After the initial surgery for which she used her savings to pay the RM5000.00 bill, she opted to receive the rest of her treatment at the study site, as she could not afford the costs in the private hospital. The other respondent had her surgery bill of RM200.00 paid by her son-in-law.

Chemotherapy

25 respondents (69%) reported that they either had completed or were undergoing chemotherapy at the time of the interview. Of these, nine respondents had completed six cycles, one had completed eight cycles, two had ten cycles, three reported that they were still undergoing their planned six cycle chemotherapy regimens while the rest did not mention the number of cycles that had been planned (10 respondents). Four respondents did not talk about chemotherapy at all and only three respondents reported having to pay for chemotherapy sessions (RM130.00, RM200.00 and RM300.00 respectively).

Radiotherapy

A total of 14 (35%) respondents reported that they had received radiotherapy and out of this number only three reported paying between RM700.00 to RM8000.00. One respondent who reported spending an estimated RM8 000.00 on radiotherapy which is higher than the recommended fees chargeable but further qualitative analyses revealed that she had received radiotherapy treatment in a different state and the amount reported also included other investigative procedures, her travelling and hospital

accommodation fees. One respondent claimed that she was unable to pay for the radiotherapy treatment prescribed because she could not afford it.

Traditional / Complimentary Treatments

Over half of the respondents (56.4%) reported no expenses on traditional/complimentary therapy but on qualitative analysis, only 12 (30%) denied consulting any traditional/ complimentary medical practitioner. Sixteen respondents (40%) reported seeing a traditional Malay practitioner ('shaman' or both shaman and masseuse) and one Chinese respondent had visited a traditional medicine practitioner (it was not clear whether she had consulted a traditional Chinese medicine Practitioner but she reported practicing "Qi Gong" when asked specifically about traditional medicine).

Nine respondents reported spending money on complimentary treatments to treat the side effects of chemotherapy. The amount (median: RM325.00; IQR: RM1260.00) spent on these complimentary treatments was slightly higher than the reported amounts spent on the traditional healers (median: RM44.00; IQR: RM127.50). However for some of the respondents consulting 'shamans', there was a great deal of travelling as the 'shamans' were in other states and these travelling expenses were not taken into account when the respondents gave their estimated cost of seeing the healers.

Monthly Non-Medical Expenses

All the respondents reported non-medical expenses and these were categorized as shown in Table 6. Some of the items that the respondents reported buying included more nutritious food such as buying more fruits and vegetables and multivitamin supplements. One respondent even reported buying health supplements from one of her healthcare providers. An unusual expense that was reported by a respondent was buying bottles of mineral water for bathing.

The travelling expenses were analyzed further (Table 7). Three respondents lived outside Kelantan and travelled for their treatments and follow-up appointments. Two travelled from the neighboring state of Terengganu and would make it a day trip unless the chemotherapy session ended late, then they would stay overnight in a hotel or at a relative's house and return home the next day. One respondent resided normally in Kuala Lumpur but stayed with her sister in Kelantan when she came for treatment. Another respondent who normally resided in Kuala Lumpur had moved to Kelantan to stay with her son since her cancer was diagnosed. More than half of the respondents could not estimate the costs of travel as they were driven to the hospital by family members or neighbors and did not have to pay for petrol costs. One respondent reported that her petrol costs had reduced since she was ill as she did not have to commute to work and the hospital was close to her house.

A study in Australia reported that travelling distance to the hospital of more than two hours and living away from home for treatment inflicted significant financial difficulties to the patients, and to some, the travelling distance was a factor that affected the decision to decline a particular cancer treatment (Zucca *et al.* 2011). However, the study did not explore if the patients had utilized the travel and accommodation assistance schemes available to cancer patients in the country. In our study, travelling expenses do not seem to indicate significant financial burden on the patients.

Table 4 Estimates of treatment charges for procedures that breast cancer patients undergo

	Cost
Surgery:	
Mastectomy	RM 4150.00 (maximum)
Excision biopsy	RM 325.00 - RM 755.00
Anaesthesia	RM 1355.00 (maximum)
Chemotherapy (adjuvant)	drug costs:
based on basic regimen – cyclophosphamide, doxorubicin and 5 Fluorouracil	RM250.00 per cycle [majority undergo 6 cycles]
Other supportive medications (pain killers, anti	

emetics [to prevent vomiting] etc)	RM400.00 – RM 2 500.00 per cycle [depends on the type and market price of the drugs]
Radiotherapy	RM 2000.00 – RM 5 000.00 per course [depends on type of radiotherapy]
Investigative procedures	
Body scan	RM 900.00 – RM 1 100.00 per procedure
X-ray (different types including mammography)	
Ultra sound	RM40.00 – RM260.00 per procedure
Blood Investigations	RM25.00 –RM 75.00 per procedure RM38.00 – RM360.00 [depends on type]

Adapted from Private Healthcare Facilities and Services (Private Hospitals and Other Private Healthcare Facilities) (reference 7) Regulations 2006 (Malaysia, 2006)

Table 5 Reported expenses of breast cancer patients

Expenses	Range (RM)	% Reporting No Expenses (RM0.00)
Total medical (including chemotherapy, radiotherapy, investigative procedures etc)	130-10 500	81.1
Surgery	200-5 000	94.1
Chemotherapy costs	130-300	91.7
Radiotherapy costs	700-8 000	92.3
Total spent on traditional/complimentary Treatments	20-2 000	56.4
Monthly non medical expenses during follow-up or treatment at hospital (e.g.transport to hospital, non-prescription dietary supplements, accommodation etc)	5-3 000	3.0

Table 6 Types of non-medical expenses reported

	Frequency (n=40)
Supplements (fortified milk, multi-vitamins, antioxidants, honey etc)	18 (45%)
Food (above the normal monthly budget for food)	17 (42.5%)
Travelling (petrol costs or public transport fares)	40 (100%)
Accommodation	2 (5%)
Breast prosthesis	2 (5%)
Others (pocket money for family members who were her caregivers)	1 (2.5%)

Table 7 Travelling

	Frequency N=40	Median (IQR)
Distance(km)		17.5 (26.25)
0-9	5	
10-49	14	
>50	8	
missing/don't know	13	
Time spent on journey (hr)		0.5 (1.67)
<0.5	7	
0.5 – 1	17	
>1	13	
missing	3	
Monthly expenses incurred for trips to hospital (RM)		RM50.00 (RM80.00)
<50.00	11	
51.00-100.00	4	
>100.00	3	
missing	22	

Table 8 Sources of financial assistance

Sources	Frequency (%) (n=40)
Government subsidized	
-Welfare Department	5* (12.5%)
-Employee or retired employee (has guarantee letter)	4 (10%)
-Husband or child a Government employee or retired employee (has guarantee letter)	8 (20%)
Private company (Employer)	1 (2.5%)
MAKNA	1 (2.5%)
Family	
-children	2 (5%)
-other family members (siblings, cousins etc)	2* (5%)
No external financial support	18 (42.5%)

*One patient reported financial support from the Welfare Department and family members

Sources of Financial Assistance

22 respondents reported getting some form of financial assistance. Either the majority of them (77.3%) received assistance from the Government in the form of direct welfare aid or they were eligible for free medical treatment by virtue of them being either government employees or the spouse or mother of a government employee. One respondent had two sources of financial help (welfare department and family members) whilst the others only reported a single source (Table 8).

The reported total medical expenses of 15 respondents with no external financial support (there were three missing reported medical expenses) ranged from RM0.00 to RM10, 500.00 as nine respondents who reported no financial assistance also reported no expenses related to treatment. Further qualitative analysis on these nine respondents who claimed no financial assistance and no medical expenses revealed that seven of them were indeed eligible for subsidized treatment as they were government employees and this increased the percentage of respondents who received financial assistance from the Government to 72% (from 42.5%). The other two had reported monthly family incomes of RM300.00 and RM500.00 respectively; and neither had been asked to pay for the treatment that they had received at the hospital.

The reported quantum of expenditure on medical expenses by the rest who claimed no financial assistance was still lower than the estimated treatment costs (Table 4) which indicates that these respondents also had the treatment costs partially subsidized but they were probably unaware of this.

Employment Related Impact

Besides having to face the challenges, anxieties, fatigue and probably fear of death because of breast cancer, some of the respondents also have to deal with economic impact such as treatment-related expenses, loss of employment and consequent income, and budget related impacts. Different types of economic impact on the respondents are given in Table 9. The disease in one way or another affected all the respondents who were working prior to the diagnosis of breast cancer. The most seriously affected were cases where respondents lost their jobs. This involved seven or 17.5% of them in our sample. This also implies all seven who completely lost their jobs, lost all their income. One respondent who managed to change her job was reported to lose more than 50% of her income. Below are some of their expressions, which indicate that they lost their jobs because of their illness.

K04 : *'After becoming ill I stopped working. That day I took leave, feeling sad'*

K07: *‘Possible, but I was feeling very tired, so I stopped, besides my two children are Already working, so I stopped. I don’t want to force myself to work’*

K10 : *‘I earned about RM30 each morning. Eh..Ever since I was ill, I have stopped Working.’*

K29: *‘At the moment I am not doing it because I am ill, so I can’t do it, my younger Sibling is doing it; I passed it over to her/him.’*

All the 11 respondents who were fortunate to obtain medical leave were working with the government because the all civil servants are entitled to a maximum of 2 years medical leave as a result of critical illnesses such as cancer.

K02: *‘But K’zah was given the choice, K’zah said K’zah would like to take 1 year leave.’*

K06: *‘No, I didn’t take leave...just took MC, but now, I am taking the cancer leave.’*

Six respondents were forced to reduce their working hours as a result of their conditions and five of them suffered a pay cut of between 25-50% and only one respondent who was working in the public sector did not suffer a pay cut. However, one respondent who was working in the private sector took unpaid leave and she claimed an income reduction of more than 50% because of that. Thirty five percent of the sample were not affected as they were either retired (two_of them) or had not been working before they fell ill.

Table 9 Prevalence economic impacts on patients

Economic Impact	(n = 40)
<i>Employment-related</i>	
Stop working on own initiative	7 (17.5%)
Reduction in working hours	6 (15.0%)
Medical leave	11 (27.5%)
Unpaid leave	1 (2.5%)
Change job	1 (2.5%)
Not working	12 (30.0%)
Retired	2 (5.0%)
<i>Income Loss</i>	
25-50% pay cut	5(12.5%)
More than 50% pay cut	2(5.0%)
100% pay cut	7(17.5%)
No pay cut	12(30.0%)
Not related	14(35.0%)
<i>Budget-related impacts</i>	
Asset sales	3 (7.5%)
Delays in payments of essential services	6 (15.0%)

Economic Impact	(n = 40)
Use of savings	3 (7.5%)
Indebtedness	7(17.5%)
Forced to hire maid	6(15.0%)

Table 10 and 11 show that all the seven respondents who lost their jobs have education levels at the most up to secondary school, two of them had not been to school at all. All of them were self-employed except for one who was working as a clerk before she stopped working. She had to stop working when she was first diagnosed with breast cancer in 2001. The reason she gave was she needed to take leave too often to go for her chemotherapy and radiotherapy treatments and she lives about 160 km from the hospital.

Reduced working hours	0	0	1	4	1	0	6
Changed job	0	0	1	0	0	0	1
Retired	0	0	0	1	1	0	2
Not working	0	8	0	4	0	0	12
Total	2	8	2	19	4	5	40

She was feeling tired most of the time. This respondent together with another six other respondents are from relatively poor families where one had a family monthly income of about RM1000, another one RM800 and the rest between RM500-700. They were mainly rubber tappers, doing small businesses like selling local cakes (*kuih-muih*) and a tailor. Only one of the patients used to have a family monthly income of about RM4000 before her illness. Unfortunately, she has to face a 50% drop in her family income when she stopped doing her food catering business where she used to earn around RM2000 per month. Four out of five respondents who claimed that they suffered a 25-50% reduction in their income revealed their monthly family income levels. The minimum income level as RM360 and the maximum only at RM2200.

For those under the 'not working or retired' category, seven out of 14 of them were willing to state their family income levels. As shown in Table 12, one of them claimed to have a monthly family income level at as low as RM120. Overall, five out of seven respondents were from families with monthly household income less than RM1000.

Based on the above discussion we noticed that patients who were from the poor economic backgrounds mainly experienced the impact of job loss and partial income loss. Even those who were not working or retired were not in any better financial situation. Thus, these imply that breast cancer has affected women in the low economic background and thus the disease can have adverse consequences on their situations where it can push the patients' families into deeper poverty.

Table 11 Impact of breast cancer on career by employment sectors

	Employment sector				Total
	Public Sector	Private Sector	Self Employed	Not Working	
Stop work on own initiative	0	1	6	0	7
MC	11	0	0	0	11
Unpaid leave	0	1	0	0	1
Reduced working hours	1	1	4	0	6

Changed job	0	1	0	0	1
Retired	2	0	0	0	2
Not working	0	0	0	12	12
Total	14	4	10	12	40

Table 12 Monthly family income for those not working and retired

Not working or retired	Monthly family income
1	3000.00
2	800.00
3	1500.00
4	900.00
5	300.00
6	360.00
7	120.00

Budget Related Impacts

Almost all except one of the respondents who lost their jobs as a result of breast cancer have budget related problems in one way or another. Out of the seven respondents who lost their jobs four of them actually have to borrow and also had delayed their payments for essential services such as telephone, water, electricity, rental or loans. None of them claimed to have used up their savings or sold any of their assets. Unfortunately we could not establish whether these respondents had any assets or savings in the first place.

K11: *‘All delayed (bill payments)Ha, water bills three months, electricity bills, three months.’*

K12: *‘I have not gone home...feel like going back as I haven’t been home for a long time, miss home a lot, but, there the electricity supply and water bills have not been paid, I’m afraid they have disconnected the supplies. Ha, we used to have a phone line, all has been disconnected, all gone, left only the mobile phone.’*

This study also indicates that only three out of the 40 respondents used up their savings to supplement their increasing expenditures as a result of this illness. One of them used her bank savings; one from her Employees Provident Fund (EPF) and another one took her savings from the *Tabung Haji*. On the other hand, seven of them either borrowed or have taken loans as the result of financial difficulties. Four of them borrowed from their siblings, one from her employer and the other two have taken a bank loan and a government loan respectively.

Breast cancer has also taken a toll on women’s abilities to do their normal household chores. Six of the patients had to hire domestic helpers to do the chores and care for them. This expense will actually add on to their financial burden. Only two of them who hired helpers were from the group where their employment and income were affected by this illness. The other four patients did not suffer adverse effects on their employment or income.

Conclusion

In Malaysia, public health care services are heavily subsidized. Breast cancer patients can seek treatment either free-of-charge in public hospitals or only pay a minimal amount unless a nonstandard regimen and other supportive medications are requested by the patients. If patients were to seek treatments in the private hospitals, costs for treating cancer can be as high as RM300, 000.00 (*The*

Star, 21 December 2011). Patients could be covered fully or partially if they have private insurance, if not it will be an out-of-pocket payment. In other countries such as Australia, Canada and some of the European countries health care funding involves a combination of universal health insurance that is provided to all citizens and optional private insurance. In the US, the Medicare and Medicaid programmes insure older citizens for health care but no national health service or insurance exists, and health insurance is most often organized through employers (Gordon *et al.* 2007). Similar to the US, this study found that older persons in Australia with cancer also face significant out-of-pocket expenses and additional hidden costs, despite most being covered by private health insurance.

In this study, even though about 81.1% of the respondents had their treatment costs fully covered, it is found that the economic impact of breast cancer on the household of the respondents was still quite substantial. Among the impacts detected were loss of jobs, reduction of working hours or prolonged medical leave. Job loss implies complete loss of income and reduction of working hours whereas changes of job may imply partial loss of income. In this study, apart from the government servants, the majority of women who had been working prior to their diagnosis of cancer reported losses of income.

Most of the respondents were from a relatively poor background. Out of the 31 respondents who gave their estimated household income, 10 (32.2%) of them were surviving with a household income of less than RM1, 000 per month. Unfortunately, most of them who suffered full or partial loss in their income were from the lower income group. Those who were not working or retired were also from the lower income group. For these families, the adverse economic impact of the illness may result in falling into poverty, a process that has been referred to as “the medical poverty trap” (Whitehead *et al.*, 2001). For those whom were already living below the poverty line, the chances of moving out of poverty might diminish once confronted with this illness (Kabir *et. al.* 2000).

Besides losing household income, breast cancer patients also faced greater expenses because of the illness, which may lead to substantial financial strain particularly if they were self-employed. Some of them used up their savings, borrowed and delayed their payments for essential services such as telephone, water, electricity, rental or loans.

Although this study did not find any breast cancer survivors reporting any disruption in their dependents' higher education or schooling activities, this may be a future issue. Recent cancer registry reports indicate that breast cancer has been diagnosed in younger women who are likely to have children of school-going age. (Penang State Health Department, 2005, 2010)

The study was unable to assess whether the increased economic burden because of this illness affects treatment compliance as all the participants were sourced in the hospital and thus were ‘compliant’. It is possible that the economic impact described by the participants will be a factor that contributes to delays in diagnosis for some women even though breast cancer screening facilities are available in Malaysia.

In Malaysia, breast cancer patients' assistance, in the form of economic and psychosocial supports, are provided by non-governmental organizations (NGOs) such as MAKNA (National Cancer Council Malaysia), BCWA (Breast Cancer Welfare Association Malaysia) and NCSM (National Cancer Society Malaysia). These agencies provide emotional, social and material support for individuals with breast cancer. Effectiveness of reaching out to certain targeted group has been a problem. Suriati *et al.* (2009) found that the majority of cancer patients were unaware that assistance was available from NGOs and further concluded that the insensitivity and inefficiency of respective agencies in providing help made it more difficult for them to seek assistance, in particular, the rural population.

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References

- Ashing-Giwa, K.T., Padilla, G., Tejero, J., Kraemer, J., Wright, K., Coscarelli, A., Clayton, S., Williams, I. & Hills, D. (2004). Understanding the breast cancer experience of women: A qualitative study of African American, Asian American, Latina and Caucasian cancer survivors. *Psycho-Oncology*, 13(6), 408-428.
- Gordon, L., Scuffham, P., Hayes, S. & Newman, B. (2007). Exploring the economic impact of breast cancers during the 18 months following diagnosis. *Psycho-Oncology*, 16, 1130-1139.
- Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C.C., Willan, A., Viola, R., Coristine, M., Janz, T. & Glossop, R. (2004). Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal*, 170 (12), 1795 - 1801.
- Hensley, M.L., Dowell, J., Herndon, J.E. 2nd, Winer, E., Stark, N., Weeks, J.C. & Paskett, E. (2005). Economic outcomes of breast cancer survivorship: CALGB study 79804. *Breast Cancer Research and Treatment*, 91(2), 153-161.
- Kabir, A., Rahman, A., Salway, S., & Pryer, J. (2000). Sickness among the urban poor: A barrier to livelihood security. *Journal of International Development*, 12, 707-722.
- Lauzier S., Lévesque P., Mondor M., Drolet M., Coyle D., Brisson J., Mâsse B., Provencher L., Robidoux A., & Maunsell E. (2013). Out-of-pocket costs in the year after early breast cancer among Canadian women and spouses. *Journal of National Cancer Institute*, 105, 280-292.
- Maunsell, E. (2009). *The impact of breast cancer on financial status of patients and their families*. Retrieved from <http://jncicancerspectrum.oupjournals.org>.
- Moore K.A. (1999). Breast cancer patients' out-of-pocket expenses. *Cancer Nurs*, 22, 389-396
- Penang State Health Department. (2005). *Penang Cancer Registry Report 1999-2003*. Ministry of Health.
- Penang State Health Department. (2010). *Penang Cancer Registry Report 2004-2008*. Ministry of Health.
- Suriati, G., Colonius, A., Narimah, S., Norizan, M. N., Azlinda, A., Intan, H.H., & Khairiah, S. M. (2009). *Kesengsaraan berganda-kemiskinan dan kanser: Satu tinjauan ke arah tindakan*. Research Report of Joint Research Majlis Kanser Nasional (MAKNA) – Universiti Sains Malaysia USM.
- The Star*. (2011). *Life, Unexpectedly*. Retrieved from <http://thestar.com.my/health/story.asp?file=/2011/12/21/health/10104748&sec=health>
- The Star*. (2009). *The Economics of Cervical Cancer*. Retrieved from <http://thestar.com.my/health/story.asp?file=/2009/3/22/health/3498085&sec=health>
- The Star*. (2008). *Breast Cancer Resources*. Retrieved from <http://thestar.com.my/health/story.asp?file=/2008/6/29/health/21646257&sec=health>
- Whitehead, M., Dahlgren, G. & Evans, T. (2001). Equity and health sector Rreforms: Can low-income countries escape the medical poverty trap? *Lancet*, 358, 833-836.
- Yip, C.H., Mohd Taib, N. A., & Mohamed I. (2006). Epidemiology of breast cancer in Malaysia. *Asian Pacific Journal of Cancer Prevention*, 7 (3), 369-374.
- Zucca A., Boyes A., Newling G., Hall A., & Girgis A. (2011). Travelling all over the countryside: Travel-related burden and financial difficulties reported by cancer patients in New South Wales and Victoria. *Australian Journal of Rural Health*, 19, 298-3