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NOTA PENYELIDIKAN/*RESEARCH NOTE*

THE SOCIOECONOMIC IMPACTS OF BREAST CANCER ON BREAST CANCER PATIENTS IN PENANG

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Breast cancer is a major cause of death and is the most common type of cancer among Malaysian women, accounting for more than 30% of newly diagnosed cancer cases in this population. In 2006, the National Cancer Registry recorded 3,525 cases of female breast cancer in Peninsular Malaysia. In addition to facing uncertainties, anxieties, possible disabilities and the fear of death, some breast cancer patients must deal with increased treatment-related expenses, loss of employment and consequent loss or reduction of income. This study examined the socioeconomic impact of breast cancer on breast cancer patients in Penang, Malaysia. The study involved 60 respondents, including 20 patients undergoing treatment at private hospitals and 40 patients undergoing treatment at public hospitals. Data were collected using guided interviews, which were later quantified for further analyses. Our study showed that all of the respondents who were working prior to their diagnosis were adversely affected. The most seriously affected patients were those who had to stop working and consequently lost 100% of their incomes. 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 lower income groups and were either self-employed or working in the private sector. The financial burdens resulting from extra medical and non-medical expenses and lost income caused financial difficulty for some respondents. Despite these adverse economic impacts, the respondents appeared to have coped relatively well socially. They also claimed to have adequate support from family and friends.

Keywords: socioeconomic impact, breast cancer patients

INTRODUCTION

Breast cancer is a major cause of death and is the most common type of cancer among Malaysian women. It accounts for more than 30% of newly diagnosed cancer cases in the country. In 2006, the National Cancer Registry recorded 3,525 cases of female breast cancer in Peninsular Malaysia. Based on the National Cancer Registry of Malaysia data, the age-standardised incidence rate (ASR) was 46.2 per 100,000 women in 2004. However, the rate differs between the three major races (Malay, Chinese and Indian). The age-standardised incidence was highest among Chinese women, at 59.7 per 100,000, followed by Indian women at 55.8 per 100,000. Malay women had the lowest incidence of breast cancer, at 33.9 per 100,000. These incidences translate into 1 in 16 Chinese, 1 in 16 Indian and 1 in 28 Malay women developing breast cancer at some stage during their lives (Cheng, Nur Aishah and Ibraham, 2006). The same study also indicates that the disease is prevalent among older women in many developed nations, but in Malaysia, 52.3% of the cases of breast cancer involve women younger than 50 years of age, with women 40–49 years old as the most commonly affected age group.

In addition to facing uncertainties, anxieties, possible disability and the fear of death, some breast cancer patients must deal with increased treatment-related expenses, loss of employment and consequent loss of income. Some women may find that they cannot perform their normal responsibilities as mothers or daughters and some may even face different treatment from their spouses, friends and relatives. This disease could have dramatic financial consequences for some patients and their families, including falling into debt or poverty.

The economic impact of breast cancer is actually a double-edged sword, with families losing household income and facing greater expenses. There are several reasons why we believe that understanding the economic impact of breast cancer on patients and their families is important. First, financial burdens may contribute to patients' decisions about treatment and recovery. Second, treatment processes may affect patients' ability to continue to work, resulting in job and income losses. Prolonged primary and adjuvant treatment for breast cancer may cause further disruption to workplace activities and earnings. Third, for patients from lower income groups, a loss of income may cause them to fall into poverty, a process that has been referred to as "the medical poverty trap" (Whitehead, Dahlgren and Evans, 2001).

Understanding the social impact of breast cancer is also important for health and social policies. Adequate physical, psychosocial and financial support from caregivers is also crucial for a patient's recovery process, which can be translated to increasing responsibilities and burdens for caregivers.

According to a report from the American Cancer Society and the LIVESTRONG organisation, which is based on data from the World Health Organization (WHO), it was concluded that cancer has a greater economic impact due to premature death and disability than all other causes of death worldwide (Medscape Medical News, 2010). The top three cancers that have the greatest global economic impacts are lung cancer, colorectal cancer and breast cancer. A study on Canadian women diagnosed with early breast cancer found that, on average, these women lost more than a quarter of their typical incomes during the first 12 months after their diagnoses (Maunsell, 2009). Those who were more likely to suffer large wage losses were those who 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, worked part-time or were recently hired at their current jobs. In Australia, the main economic impacts on individuals with breast cancer were a loss of income followed by out-of pocket costs for health services (Gordon, Scuffham, Hayes and Newman, 2007). This study also indicated that younger women (less than 50 years old) were more vulnerable in terms of large economic burdens after a breast cancer diagnosis. In the U.S., older patients face significant out-of-pocket expenses, particularly for medications and home services (Moore, 1999). Other studies have shown the adverse effects of breast cancer on employment and income (Bradley, Bednarek and Neumark, 2002; Hensley, Dowell, Herndon, Winer, Stark, Weeks and Paskett, 2005). 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 impacts on caregivers of breast cancer patients in Canada and showed that 69% of employed caregivers reported some form of adverse impact on their work.

In Malaysia, most studies have concentrated on the clinical aspects of the disease but not the economic burdens on the patients. 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*, 2009). The team was responsible for developing an economic model encompassing the costs of cervical cancer disease that were attributable to HPV infection and to conduct a health economics study on HPV vaccination in Malaysia.

Gathering local data on breast cancer is crucial for determining the burden of breast cancer illness, as it is the most common cancer affecting women in Malaysia. Those who are most strongly affected by the disease are the patients themselves, their family structures and their children. The economic stability of the family is an issue because many women in Malaysia work to earn income.

Women with breast cancer can foster economic problems in the wider community because many of these women cannot work during breast cancer treatment or cannot return to the work force even if they survive. In addition, there are high frequencies of morbidity and mortality for these patients. Understanding the economic impacts of breast cancer may help those diagnosed with the disease plan for anticipated costs and may also enable health professionals to identify women who might benefit from government support programs.

In Malaysia, women 40–49 years of age are the most common age group affected by breast cancer. The detection of breast cancer at younger ages means that women in the labour force might sustain greater losses. Therefore, the question arises whether breast cancer causes job losses, reduces work effort or diminishes the earning capacities of patients.

Several studies have shown that the socioeconomic impact of cancer on the family might adversely affect patients' treatment compliance. If treatment compliance is affected by socioeconomic factors, these patients will not only face increased socioeconomic problems, but they may also have a poorer quality of life and a reduced chance of survival.

OBJECTIVES AND DATA COLLECTION

Our research objectives were to describe the sociodemographic characteristics of breast cancer patients and analyse the socioeconomic impacts of breast cancer treatment. We began with the objective of studying the socioeconomic impacts of breast cancer on patients and their families in Penang, and we planned to analyse the effects of these socioeconomic impacts on compliance with breast cancer treatments such as radiotherapy and chemotherapy. However, our data showed that almost all patients complied with their treatments. This finding may be the result of a bias in our data collection method because we interviewed patients at hospitals (these patients were the most likely to comply because they were at hospitals to seek treatment). Our focus was then changed to determine the socioeconomic impacts of breast cancer on breast cancer patients. We assessed the reported expenses and the sources of financial aid that they obtained. We measured the impacts of the illness on aspects such as employment, income, savings, household budget and household responsibilities and explored the social impacts of the disease, such as their relationships with spouses, friends and neighbours. We also determined whether they joined any breast cancer support groups in Penang. This study aimed to contribute to a better understanding of the socioeconomic problems faced by breast cancer patients and their families in Penang. Studying socioeconomic factors adds an important dimension for understanding the impact of breast cancer and these findings could be used to improve supportive care services for the women and families who are affected by this disease.

Participants were purposely sourced from four hospitals with oncology services in Penang. Two hospitals were in the private sector, and two were government hospitals. These hospitals granted permission to perform the study, and the staff assisted in introducing the researchers to potential participants who had been diagnosed with breast cancer. A total of 60 participants were interviewed by trained enumerators using a guided questionnaire format, and the participants were encouraged to elaborate on their answers as much as possible. The patients were approached while they were waiting for their follow-up appointments with their doctors. After informed consent was obtained, interviews were conducted and were recorded and transcribed.

The guided questionnaire comprised four main parts. The first part explored the socioeconomic backgrounds of the respondents and included information related to the cancer diagnosis. The second part focused on the economic impacts of breast cancer, including work-related issues, treatment expenses and household expenses since the diagnosis. The social impacts of the cancer diagnosis on the respondents were explored in the third part, and the socioeconomic impacts on immediate caregivers, spouses and other family members were examined in the fourth part.

RESULTS AND DISCUSSION

The Patient Profile

In total, 40 respondents were recruited from two government hospitals, and 20 were recruited from two private hospitals in Penang. The ages of the respondents ranged from 34 to 71 years, with a mean age of 52.5 (SD 8.94) years. Most of the patients had Malay or Chinese racial backgrounds. About 95% of the respondents had attended school before and at least at the primary school level. The majority of them (35%) had formal education up till upper secondary. [In the Malaysian school system, primary education is from age 7 to 12 (Standard 1 to 6) and lower secondary education from age 13 to 15 (Form 1 to 3 and upper secondary education from age 16 to 18 (Form 4 to 6)]. A large majority (76.7%) of the respondents were married; the rest were either single or widowed. The details of race, highest education level and marital status are presented in Table 1.

Table 1: Racial distribution and education levels of the respondents (*n* = 60)

Variable	**Frequency (%)**
Race	
Malay	26 (43.3)
Chinese	24 (40.0)
Indian	10 (16.7)
Total	60 (100.0)
Highest education level attained	
No schooling	3 (5.0)
Primary schooling	14 (23.3)
Lower secondary schooling (Forms 1–3)	14 (23.3)
Upper secondary schooling (Forms 4–6)	21 (35.0)
Certificate*	1 (1.7)
Diploma*	6 (10.0)
Degree*	1 (1.7)
Total	60 (100.0)
Marital status	
Married	46 (76.7)
Single	7 (11.7)
Widowed	7 (11.7)
Total	60 (100.0)

*Certificate or diploma education is from age 17 onwards (after form 5 or 6) and Bachelors' degree from age 19 or 20 (after form 6 or diploma)

With regard to employment, the largest group was made up of patients who were not working at the time of diagnosis, followed by patients who were working in the private sector. The rest of the respondents were either working in the public sector or were self-employed. When further analysed by hospital sector, the majority of respondents from government hospitals were not working, while half of the respondents from private hospitals worked in the private sector. Table 2 shows the employment sectors of all respondents as well as employment sectors by hospital type. The overall monthly personal incomes of respondents (for the 25 respondents who were working and responded to this question) ranged from RM450 to RM10,000 and the distribution was skewed to the right (i.e., the majority of respondents had low incomes). The monthly family income (for 50 respondents who responded to this question, including those who were not working or retired) ranged from RM150 to RM10,500 which demonstrated a similar distribution pattern. As expected, the monthly personal and family incomes of respondents from private hospitals were higher than those of respondents from government hospitals. The income details of the respondents are shown in Table 3.

Table 2: Employment sectors of the respondents ($n = 60$)

Variable	Frequency (%)
Overall employment sector	
Not working	28 (46.7)
Private	18 (30.0)
Public	7 (11.7)
Self-employed	7 (11.7)
Total	60 (100.0)
Employment sectors of respondents from government hospitals	
Not working	25 (62.5)
Private	8 (20.0)
Public	4 (10.0)
Self-employed	3 (7.5)
Total	40 (100.0)
Employment sectors of respondents from private hospitals	
Not working	3 (15.0)
Private	10 (50.0)
Public	3 (15.0)
Self-employed	4 (20.0)
Total	20 (100.0)

Table 3: Monthly incomes of respondents and families by hospital sector ($n = 60$)

Variable	Government hospital (RM)	Private hospital (RM)
Respondents monthly income	$n = 11$	$n = 14$
Range	500.00–2,500.00	450.00–10,000.00
Median (IQR)	1,200.00 (1,200.00)	1,350.00 (2,750.00)
Mean (SD)	1,309.1 (654.9)	2,560.71 (2,674.68)
Family monthly income	$n = 34$	$n = 16$
Range	150.00–5,000.00	600.00–10,500.00
Median (IQR)	1,500.00 (1,775.00)	2,200.00 (6,000.00)
Mean (SD)	1,800 (1,270.7)	3,768.75 (3,757.79)

IQR = Interquartile range; SD = Standard deviation

The number of children (including stepchildren and adopted children) of the respondents ranged from 0 to 6, but the most common number of children was four (30.0% of the respondents). However, the qualitative data suggested that many of these children were adults and were no longer in school. Eight respondents reported having at least one other dependent, including parents, a grandson, a niece or a nephew to whom they provided financial assistance.

The year in which the respondents were diagnosed with breast cancer ranged from 1994 to 2009, but most of the respondents were diagnosed within the 12 months prior to the interviews (35.6% were diagnosed in 2008 or 2009). Regarding the cancer stage at the time of diagnosis, most of the respondents were diagnosed at stage 1 (33.3%), followed by stage 2 (26.7%), stage 3 (18.3%) and stage 4 (5.0%). Approximately one sixth of all respondents (16.7%) were not sure of their cancer stage at the time of diagnosis. The reasons obtained from the qualitative data for being unsure included not seeking this information from the doctor or receiving conflicting information by different doctors.

ECONOMIC IMPACTS

Expenses

Breast cancer treatment is individualised to each patient, and conventional medical treatment expenses comprise the following: surgery costs that may involve a lump removal or a whole breast removal (mastectomy); anaesthetic costs; chemotherapy costs (which depend on the type of drug regimen and number of cycles of treatment); and, possibly, radiotherapy costs (which depend on the number of cycles and courses prescribed). Medical expenses also include the investigative procedures that the doctor requires to correctly diagnose and stage the patient as well as the related medications required to manage the side effects of cancer treatment. Expenses for traditional/complimentary medical treatment were specifically requested, but only two patients reported their expenses, and one respondent did not give an answer. Non-medical expenses included all other expenses that were reported by the respondents as being spent because of breast cancer but could not be classified as medical expenses.

There was a wide range of reported expenses, as shown in Table 4, which is likely due to the fact that the respondents were sourced from four different hospitals. Two were government hospitals, where treatment costs are partially or completely subsidised (for retired or active public servants), and the other two were private hospitals, where treatment costs are covered by the individual, who may or may not have health insurance coverage.

Only estimated expenses can be reported; many respondents claimed that they did not know the treatment costs because they was taken care of by others (e.g., family or health insurance) or could not remember the costs and could only give rough estimates.

Table 4: Reported estimated expenses related to treatment of breast cancer

Type of expense	Number of respondents (*n*)	Range (RM) (median)	Number of respondents reporting RM0.00 expenses (%)
Estimated total expenses attributed to the treatment of breast cancer since the diagnosis	58	0.00–90,000.00 (650.00)	15 (25.9)
Estimated medical expenses:			
Surgery and Investigations	54	0.00–48,200.00 (100.00)	23 (42.6)
Radiotherapy	57	0.00–25,000.00 (1,574.52)*	37 (64.9)
Chemotherapy	56	0.00–60,000.00 (7,070.83)*	31 (55.4)
Estimated total expenses attributed to traditional/complimentary therapy for breast cancer	2	0.00–24,000.00 #	57 (96.6)
Estimated non-therapy expenses related to breast cancer e.g., transport to hospital, accommodation, special dietary supplements, etc.	57	0.00–2,500 (100.00)	16 (28.1)

* mean reported as median was RM0.00
# only two respondents gave an estimated expense

As there were two basic types of healthcare facilities in this study (private and public hospitals), the total medical and non-medical expenses were analysed as shown in Figures 1 and 2.

The median [IQR] estimated total expense for respondents who were being treated at government/public and private hospitals were RM150.00 [950.00] and RM32,500.00 [28,750.00], respectively. There were six outliers among the public hospital respondents, and qualitative analysis revealed that all six outliers initially sought treatment at private hospital facilities prior to continuing their treatments at public hospitals. The figures show that there is a large difference in the expenses reported by respondents who were treated at private hospitals; these respondents spent more on both medical and non-medical expenses compared to respondents who were being treated at public hospitals.

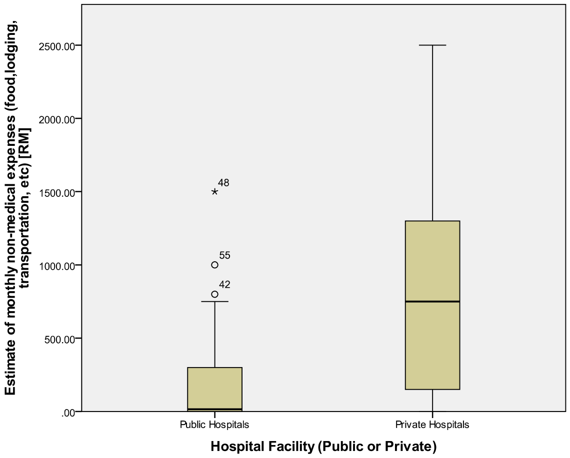

Figure 1: Reported total medical costs

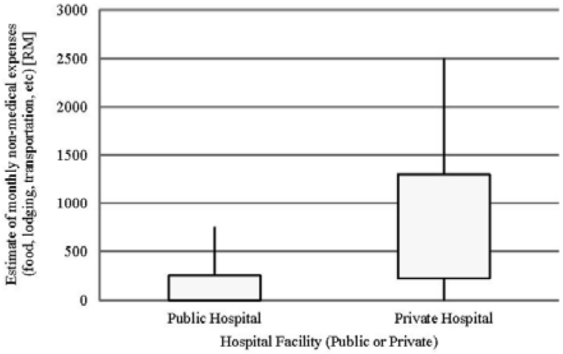

Figure 2: Reported estimated non-medical expenses

The respondents were encouraged to describe the non-medical expenses that they incurred since being diagnosed with breast cancer. Some respondents were very forthcoming and described the changes to their diet, which entailed extra expenses on food items and dietary supplements. However, the respondents could only give estimates of these expenses because the amounts changed from month to month. One of the expenses that we were interested in exploring was the amount spent on travel. We felt that this expense was a good proxy of the burden of non-medical expenses. To standardise the reporting of these expenses, we asked the respondents specific questions regarding travel expenses to the hospital for the month in which the interview was conducted. We analysed the data collected on travel according to the hospital facility. The median distance travelled and the mean duration of hospital trips appeared to be slightly shorter for the respondents who were treated at government hospitals, but the difference was not significantly different (*P* = 0.58), as shown in Table 5. Both private hospitals in this study were located on the island (Penang) on the outskirts of the town/city. One government hospital was located on the mainland and the other on the island. Therefore, respondents who lived on the mainland and received treatment at government hospitals did not need to travel to the island for treatment, which could be one reason for the shorter distances and journey durations. There was a significant difference in the estimated non-medical monthly expenses between the two groups of respondents (*P* = 0.002); the respondents who were treated at private hospitals spent a larger amount of money on travel. Three respondents in this group came from the neighbouring state of Kedah and had to spend money on lodging because travelling to and from the hospital daily for treatment was too tiring.

Table 5: Travel expenses of the respondents

	Government (Missing = 3)	Private (Missing = 1)
Distance in km:		
mean (SD)	24.8 (20.09)	34.7 (32.4)
median (IQR)	15.0 (43.00)	20.0 (52.00)
Duration of journey (hrs):		
mean (SD)	0.6 (0.35)	0.9 (0.63)
median (IQR)	0.5 (0.70)	0.8 (1.08)
Estimated monthly travel expenses including food and lodging (RM):		
median (IQR)	15.00 (300.00)	900.00 (1,150.00)
Range	0.00–1,500.00	0.00–2,500.00

Specific questions were asked regarding the financial assistance that the respondents might have received. The results are shown in Table 6. Only one respondent answered affirmatively to the direct question of whether she received government welfare aid. Thirty-four (24 from government hospitals and 10 from private facilities) respondents reported receiving no financial assistance whatsoever for treatment costs. Based on a qualitative analysis, however, it was found that of these 34 respondents, 11 who were interviewed at government hospitals had guarantee letters because they were government employees (*n* = 4) or their husbands or children were or had been government employees (*n* = 7);

therefore, they were not charged for treatment. Two respondents were eligible for free government treatment but opted to obtain private medical treatment because they felt that there would have been a delay in receiving treatment at a government hospital. One of these respondents had her treatment costs completely covered by her personal medical insurance, and the other reported no financial assistance.

A total of 13 respondents reported that their medical expenses were covered completely or partially by personal medical insurance. The majority of these respondents (77%) were interviewed in private hospitals.

Only non-government (private sector) employees might have contributed to the Social Security Organisation (SOCSO) and thus might have been eligible for SOCSO social protection schemes—Employment Injury Insurance scheme and Invalidity Pension scheme (5). The latter provides 24-hour coverage for workers for invalidity or death, irrespective of the cause, to ensure that payments are made to workers or their dependents when an unexpected incident occurs during the employee's working life. Eighteen respondents were working in the private sector and should have been SOCSO contributors, and seven more were self-employed and might have been SOCSO contributors. Contribution to SOCSO is not mandatory for self-employed individuals, but it is mandatory for employers and employees in the private sector who earn less than RM3,000 per month. It is optional for those who earn more than RM3,000 although once a person has registered with SOCSO, he or she must continue contributing throughout his or her working life (SOCSO, 2010). Only one respondent reported having had her treatment costs partly covered by SOCSO, although two others had tried to make claims. One respondent was unsuccessful because she was deemed not eligible, as she was not considered an invalid even though she had stopped working due to her illness. The other respondent was awaiting a response from SOCSO at the time of the interview.

Five respondents reported receiving financial assistance from MAKNA, which is the abbreviation for the National Cancer Council. This non-governmental organisation provides financial assistance to cancer patients who have been referred by the medical welfare departments of public hospitals. This financial assistance may be in the form of a bursary or loan from the micro-credit programme, which provides small unsecured loans.

Table 6: Financial assistance

Sources of financial assistance (number of respondents = 60)*	Frequency (%)
Welfare Department	1 (1.7)
Insurance	
- Personal Medical Insurance	13 (21.7)
- SOCSO	1 (1.7)
Employer	2 (3.3)
National Cancer Council (MAKNA)	5 (8.3)
Zakat	1 (1.7)
Informal assistance	
- Family	11 (18.3)
- Friends	3 (5)
None (11 had guarantee letters for free government hospital treatment)	34 (57)

*There were two or more sources of financial assistance for 10 respondents

One Muslim respondent reported receiving some *zakat*[1] money but did not elaborate further. One of the respondents who had medical insurance coverage mentioned that the cost of her treatment was higher because her insurance would cover her bills. "As I am claiming the medical insurance, the charge is much higher. Doctor did not benefit from it but hospital will gain." To explore this allegation, we compared the reported costs of treatments between the group with medical insurance coverage and the group with none, after excluding all cases that reported not spending anything on that particular medical treatment. As the data were not normally distributed, and there were only 7–11 respondents who had medical insurance, the non-parametric Mann-Whitney test was used to compare the two groups. The results are shown in Table 7. There were significant differences between the two groups in the estimated total costs ($p = 0.007$) and in the estimated costs of chemotherapy ($p = 0.02$) and radiotherapy ($p = 0.035$) treatments. There was a significant difference in the number of radiotherapy treatments reported by the two groups; those with medical insurance reported undergoing more treatments ($p = 0.044$). There was no difference in the numbers of chemotherapy treatment cycles between the two groups. The insured group appears to have had more cycles of radiotherapy treatment and more expensive chemotherapy treatments prescribed than the uninsured group.

A number of personal sources of financial assistance were also reported, and the impacts of job loss and income reduction, coupled with increases in expenditures, mainly for medical treatment, caused financial strain for a number of respondents. Four respondents were forced to sell their properties to cope with

Table 7: Treatment between respondents with and without medical insurance

	n	Median (IQR)	*Z*-statistic*	*p**
Estimated total medical cost (RM)	11	30K (25K)	–2.716	0.007
• With insurance	32	3.73K (70K)		
• Without insurance				
Estimated cost of operation (RM)	8	9.5K (6.88K)	–1.582	0.114
• With insurance	23	4.8K (8.85K)		
• Without insurance				
Estimated cost of chemotherapy (RM)	10	17.5K (21.25K)	–2.335	0.02
• With insurance	15	6.4K (21.68K)		
• Without insurance				
Estimated cost of radiotherapy (RM)	7	7K (5K)	–2.106	0.035
• With insurance	13	1K (5.25K)		
• Without insurance				
Number of chemotherapy cycles	10	7 (2)	–0.353	0.724
• With insurance	15	8 (2)		
• Without insurance				
Number of radiotherapy sessions	7	30 (5)	–2.105	0.044
• With insurance	13	20 (13)		
• Without insurance				

*Mann-Whitney Test

the increased expenses, and some claimed to have no assets to sell. Out of the nine respondents who used up their bank savings or their Employment Provident Fund (EPF) to finance their increasing expenditures as a result of this illness, five had also lost their jobs. Eight respondents reported that they had borrowed money. The sources of the loans included relatives, a Chinese association and banks. Four respondents needed to hire domestic help, which incurred extra expenditures. As a result of their illnesses, four respondents also had difficulties in paying their utility bills.

Impact on Career and Income

Besides having to face the challenges of added expenses coupled with anxieties, fatigue and the fear of death as a result of breast cancer, some patients also had to deal with other economic impacts, such as the loss of employment and consequent loss of income. The different types of economic impacts on the Penang breast cancer patients are shown in Table 8. All of the respondents who were working prior to diagnosis of breast cancer suffered adverse impacts on their employment in one way or another. The most badly affected were those who had to leave their jobs or were terminated by their employers.

Details of the impacts on employment are given in Table 9. Out of 29 working respondents, 11 (38%) lost their jobs and 100% of their incomes. Amongst the other 18 respondents, half were on medical leave, and the other half needed to reduce their working hours. Out of the 9 respondents who reduced their working hours, 2 had income reductions of less than 25%, 4 suffered income reductions of 25%–50%, and 1 had her income reduced by more than 50%. Most of the respondents who were still working or had been working prior to their illness felt that their employers did not treat them any differently, and 2 respondents felt that their employers have been supportive of them.

Below is an example of one respondent (48 years old) who was terminated by her employer as a result of her illness. She was the only respondent to report negative discrimination by her former employer.

> "They said I can claim SOCSO. In order to claim SOCSO I have to turn in my resignation letter. So I said, I don't want to hold all these messy things. If the job is meant for me, my employer said that I could always come back next time. I can't tell how long the treatment will go on. I was the assistant to the marketing manager, so he needs someone to replace me because if I may have to take a long time for this treatment. So I can't hold on to the job because of all these reasons. So I said ok, I'll hand over the resignation letter. But unfortunately after all this process SOCSO says I 'm not eligible to claims even though I said that I have lost my income. But they said you are not entitled to pension as you do not fall into that category [unclear] since I have not reached a serious stage yet. I lost both. Ah. I lost the job, I lost the claim also. I have just finished my treatment end of last year. So economy is bad."

Nine patients were on medical leave. Four of these patients were working with the government and were fortunate to receive medical leave because all civil servants are entitled to a maximum of two years of medical leave as a result of critical illnesses such as cancer. There was, however, one respondent who was a teacher and was not aware of the available leave, so she continued to work without medical leave. In addition, her school principal was also not aware that such people should be given lighter workloads.

That respondent underwent her treatments and operation during school holidays, and when she returned to work, few people were aware of her illness, although her principal knew about it.

The other five respondents who were on medical leave were working at private firms. Their medical leaves were based on the durations recommended by their doctors.

Table 8: Economic impacts on patients

Economic Impact	***N* = 60**
Employment-related impacts (based on those who were working prior to the diagnosis) (*n* = 29)	
Job loss	11 (38%)
Reduction in hours worked	9 (31%)
Medical leave (MC)	9 (31%)
Job change	0 (0%)
Respondents either not working or retired (*n* = 31)	
Not working	23
Retired	8
Income loss (based on those who were working prior to the diagnosis) (*n* = 29)	
Yes < 25%	2 (6.9%)
Yes 25–50%	4 (13.8%)
Yes > 50%	1 (3.4%)
Yes 100%	11 (38%)
No	11 (38%)
Budget-related impacts (*N* = 60)	
Asset sales	4 (6.7%)
Delays in payments of essential services	5 (8.3%)
Use of savings	9 (15.0%)
Indebtedness	8 (13.3%)
Forced to hire domestic help	4 (6.7%)

Among those seeking treatment at private hospitals, the average age of respondents who lost their jobs was 43.8 years, and the average age of those who were still employed was 48 years, as shown in Table 9. Even though they were younger than the respondents who kept their jobs, the impacts of their illnesses could have given them no choice but to quit their jobs. The youngest patient who had to quit her job as a result of breast cancer was 34 years old. Among those who sought treatment at public hospitals, however, those who kept their jobs had an average age of 50.3 years. Respondents who lost their jobs were older, with an average age of 54.3 years. All of the patients who lost theirs jobs were either self-employed or working in the private sector.

Table 9: Economic impact by those seeking treatments at private and public hospitals

Private hospital (*n* = 14)	**Age**	**Job loss**	**Job change**	**Work hrs reduction**	**Discriminated by employer**	**Decreased in income**
Waitress	34	Yes	–	–	Unchanged	Yes 100%
Supervisor	40	Yes	–	–	Not related	Yes 100%
Tailor	44	Yes	–	–	Not related	Yes 100%
Tailor	50	Yes	–	–	Not related	Yes 100%
Clerk	51	Yes	–	–	Not related	Yes 100%
Clerk	55	No	No	yes	Yes, positive	Yes 25%–50%
Customer service	51	No	No	Yes	Yes, positive	Yes < 25%
Training manager	46	No	No	MC	Unchanged	No
Helping at brother's shop	46	No	No	Yes	Unchanged	Yes > 50%
Lecturer	40	No	No	MC	Unchanged	No
Part-time accountant	58	No	No	Yes	Unchanged	Yes 25%–50%
Room hotel supervisor	46	No	No	MC	Unchanged	No (no pay cut)
Dealer representative	45	No	No	Yes	Unchanged	No (no pay cut)
Teacher	45	No	No	MC	Unchanged	No
Public Hospital (*n* = 15)						
Marketing Manager Assistant	48	Yes	–	–	Yes, negative	Yes 100%
Tailor	57	Yes	–	–	Not related	Yes 100%
Enumerator	51	Yes	–	–	Not related	Yes 100%
Working at a factory	52	Yes	–	–	Not related	Yes 100%
Working at a factory	61	Yes	–	–	Unchanged	Yes 100%
Working at a factory	57	Yes	–	–	Unchanged	Yes 100%
Working at a factory	52	No	No	MC	Unchanged	No (no pay cut)
Working at a factory	51	No	No	MC	Unchanged	No
Working at a factory	56	No	No	MC	Unchanged	No
JPJ (*Jabatan Pengangkutan Jalan)* Officer	52	No	No	MC	Unchanged	No
Sells nasi lemak	64	No	No	Yes	Not related	Yes < 25%
Teacher	56	No	No	No	HM (headmaster) didn't reduce workload	No
Tailor	45	No	No	Yes	Not related	Yes 25%–50%
Government officer	37	No	No	MC	Unchanged	No
Business	40	No	No	Yes	Not related	Yes 25%–50%
Total	**29**	**29**	**29**	**29**	**29**	**29**

Table 10 shows that 5 out of 11 respondents who lost their jobs had lower levels of educational achievement (lower secondary school and below), 5 had upper secondary educations, and one had a diploma. On the other hand, 14 out of the 18 respondents who kept their jobs had at least a higher secondary education qualification.

Table 10: Job loss by educational levels

Job loss	Education level							Total
	No schooling	Primary school	Secondary school (Form 1–3)	Secondary school (Form 4–6)	Cert.	Diploma	Degree	
Yes	1	2	2	5	0	1	0	11
No	1	1	2	9	0	4	1	18
Retired	0	1	3	2	1	1	0	8
Not working	1	10	7	5	0	0	0	23
Total	3	14	14	21	1	6	1	60

All of the respondents who lost their jobs were either self-employed or working in the private sector, as shown in Table 11. All five patients who were working in the government sector kept their jobs. As stated earlier, most of these patients had benefited from the two years of medical leave to which they were entitled.

Table 11: Job loss by employment sector

Job loss	Employment sector			
	Public sector	Private sector	Self employed	Total
Yes	0	10	1	11
No	5	9	4	18
Total	5	19	5	

Therefore, it appears that breast cancer had a stronger effect on women with low economic backgrounds, and the disease could have adverse consequences on their situations because it could lead to deeper financial difficulties for the respondents and their families. This finding is supported by the fact that most of the patients who had lost their jobs, were retired or were not working reported relatively low average monthly family incomes. As indicated in Figure 3, among all of the groups, those who kept their jobs had relatively higher monthly family incomes (RM4,000) compared to those who lost their jobs (RM1,945.50) or who were retired (RM1,200) or not working (RM1,527.78) (Note: 1 and 2 respondents from the 'not working' and 'retired' groups, respectively, did not give their family monthly incomes and were excluded from the analysis).

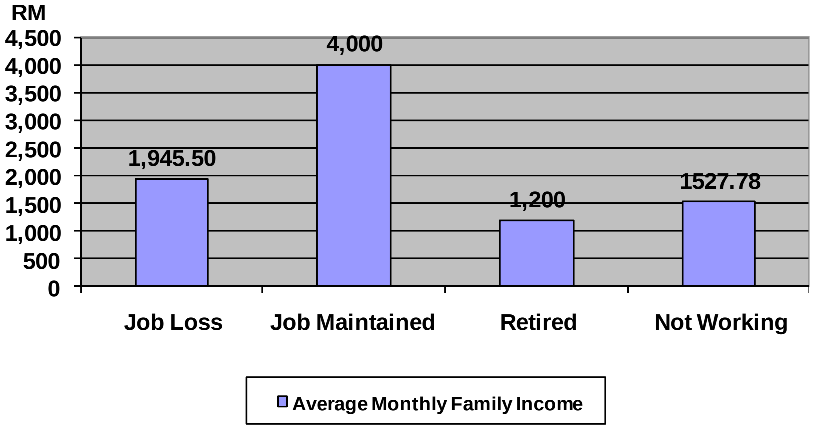

Figure 3: Monthly family income by job status

SOCIAL IMPACT

The social impacts of breast cancer on the respondents were assessed by determining whether cancer had affected their lifestyles, specifically their ability to perform daily chores, dietary changes and changes in their relationships with their spouses, family members and friends. The respondents were also asked whether they had joined or were involved with any cancer support group.

More than half of the respondents (61.7%) agreed that breast cancer had adversely affected their lifestyles. The highest impact, which was reported by 36.7% of the respondents, was on their diets (either in isolation or in combination with other impacts). The respondents reported that they had started eating more fruits, vegetables or fish and less meat after they were diagnosed with breast cancer. Some also stated that they now prepared food in a healthier way by steaming or boiling instead of frying. There were, however, some respondents who did not follow any special diet, but a few emphasised the importance of eating in moderation.

In total, 26.7% of the respondents felt that breast cancer had impaired their ability to perform housework. A review of the qualitative data indicated that most of them felt less energised, especially following chemotherapy sessions, and seven respondents had specifically mentioned that they had restricted arm movements following surgery. Another daily chore that was reported as being interrupted due to breast cancer was the fulfilment of children's daily needs. This issue, however, was not elaborated further during the interview. None of the respondents' children had to miss school because of their mothers' health conditions. This finding could be due in part to the fact that most respondents had older children. Four respondents admitted to not being able to enjoy normal recreational activities with their families due to cancer, while the rest felt that cancer did not strongly affect these activities. One respondent explained that she felt too tired and that she lost the desire to enjoy outdoor activities. Another respondent chose not to go outside because she did not feel comfortable with people asking about her condition. The respondents' health situations did not appear to have adversely affected their interactions with family members, nor had they significantly affected the health of their family members. The distributions of the effects of breast cancer on patients' lifestyles are shown in Table 12.

Table 12: Adverse effects of breast cancer on the respondents' lifestyle

Variable	**Frequency (%)**
General lifestyle	
Yes	37 (61.7)
No	23 (38.3)
Total	60 (100.0)
Dietary changes	
Yes	22 (36.7)
No	38 (63.3)
Total	60 (100.0)
Ability to do housework	
Yes	16 (26.7)
No	44 (73.3)
Total	60 (100.0)
Ability to fulfil children's daily needs (among those with children)	
Yes	10 (19.2)
No	42 (80.8)
Total	52 (100.0)
Interaction with family	
Yes	5 (8.3)
No	55 (91.7)
Total	60 (100.0)

(continued)

Table 12: *(continued)*

Variable	Frequency (%)
Recreational activities with family	
Yes	4 (6.7)
No	56 (93.3)
Total	60 (100.0)
Health of family	
Yes	3 (5.0)
No	57 (95.0)
Total	60 (100.0)
Children missing school (among those with children)	
Yes	0 (0)
No	52 (100.0)
Total	52 (100.0)

Table 13: Respondents' relationship with spouse, immediate family and friends/ neighbours

Variable	Frequency (%)
Spouse (among those currently married)	
Normal	27 (58.7)
Improved	15 (32.6)
Deteriorated	4 (8.7)
Total	46 (100.0)
Immediate family	
Normal	43 (71.7)
Improved	15 (25.0)
Deteriorated	2 (3.3)
Total	60 (100.0)
Friends/neighbours	
Normal	49 (81.7)
Improved	10 (16.7)
Deteriorated	1 (1.7)
Total	60 (100.0)

Among the 46 respondents who were "currently married," the majority reported that there was no change in their relationships with their spouses after they were diagnosed with cancer. Some respondents felt that their relationships had either improved or, in a few isolated cases, deteriorated. The same trend was observed with the relationships of all 60 respondents with immediate family members, friends and neighbours (Table 13). Many respondents agreed that they received a great deal of physical and moral support from their spouses. For example, their husbands helped in looking after the respondents' wellbeing, including encouraging them to undergo mastectomies, taking care of the respondents when they were unwell, looking after the house and the children and supporting them emotionally. Schneider, Fletcher and Snider (2008) investigated the importance of social support in the coping process of women with cancer and reported spousal support to be one of the most crucial sources of support. The authors further reported that spouses often demonstrated their support through "love, listening and encouragement," which corresponded well with our findings. One respondent, however, reported that her husband, who used to accompany her to the hospital when she first diagnosed with cancer five years ago, has stopped doing so, but no further explanation was given.

The qualitative data on the respondents' relationships with immediate family members were not comprehensive, but the few comments that were provided indicated that some respondents received support from their children. Sadly, one respondent felt abandoned because she felt that her family and in-laws did not care about her despite her condition. This could possibly be due to a lack of information about cancer, which led to rejection and isolation. However, we have no evidence to support this assumption.

The respondents also received a great deal of physical and moral support from their friends and neighbours. Their friends would try to cheer them up when they were feeling unwell, although one respondent claimed that "some of them (her friends) tend to be irritable." Two respondents believed that they had found "true friends" who were always there for them. When the working respondents were asked further about how they perceived their relationships with their employers after learning they had cancer, the comments were generally encouraging. Most felt that there was no socially negative discrimination and that their employers were generally supportive, including allowing them to take extended medical leave. One respondent, however, reported that she was accused of avoiding work by using cancer as an excuse to take long leave. The overall positive support that the respondents received is encouraging because an American study that was conducted on women with breast cancer found that those who were socially isolated had a two-fold increased risk of breast cancer mortality compared to those with stable social support systems (Kroenke et al., 2006).

With regard to joining cancer support groups, a large majority (88.3%) did not join any group; only seven respondents (11.7%) were involved as either official or unofficial members of support groups, including the National Cancer Society of Malaysia (Penang branch) and the Penang Breast Care Society. These non-profit organisations organise various cancer educational activities that are aimed to reduce the cancer burden faced by patients and their families. Among the reasons stated for not being in a support group include "I don't really know about it," "I don't know where to find it," "I don't have the time," and "I don't have the energy/I'm too weak." One respondent claimed that such groups are not available in her area (Langkawi). Another respondent specifically said that even if she had the energy, she could not afford to spend time on cancer support group activities because she has to earn money and do the household chores. Another respondent, who was also not in a support group, had expressed her wish to have someone from a group to come to her house whenever she needed support. One respondent was under the impression that she had to pay for the services of a support group. It would be interesting to explore the nature of support groups, for example, if they are government-based or non-governmental organisations (NGOs), including those established by specific ethnic or religious groups because the information could indicate the roles that these groups play in enhancing patients' quality of life. Unfortunately, we were unable to obtain sufficient information on this topic, as all seven respondents in our study were involved in NGOs that were not set up by any of these specific groups. An Australian study reported that patients regarded cancer support groups as beneficial if they could provide a supportive environment, give a sense of mutuality and belonging and meet the perceived needs of those in attendance (Ussher et al., 2006). It is interesting to note that although most of the respondents in our study claimed that they did not participate in cancer support group activities, some admitted that they had received moral support from cancer survivors who had visited them at the hospital while they were receiving treatment, stressing the importance of peer support.

The respondents were also asked to describe their attitudes or emotions upon discovering that they had breast cancer. The comments were generally positive, and the respondents could accept that they had cancer and tried not to be too depressed about their condition (e.g., "Try to look at the bright side, you have to be happy. Don't think too much about it"). Overall, the comments suggested that the respondents were willing to fight the disease.

CONCLUSION

Convincing respondents to talk about their financial situation and how breast cancer has impacted them and their families has not been an easy task, and there were a large number of breast cancer patients who refused to participate. A number of respondents reduced the interviewers to tears when recounting their personal journeys through the breast cancer treatment process. Breast cancer has definitely taken a toll on the respondents. Our study showed that all of the respondents who were working prior to being diagnosed were adversely affected by their breast cancer. The most seriously affected respondents were those who had to stop working or, in one case, was asked to leave her job. This group lost 100% of their incomes. Another group of patients suffered pay cuts because they had to reduce the number of working hours or opted to work on a part-time basis. Some suffered as much as a 50% reduction in pay, a few had decreases of 25%–50%, and some had pay cuts of less than 25%.

None of respondents who were working in the public sector lost their jobs because they are allowed to take a maximum of two years of medical leave, a practice that should be encouraged and promoted to private employers, as this practice would lessen the burden on patients. Most of the more adversely affected cases were from lower income groups and were either self-employed or working in the private sector. The average monthly family incomes of those who lost their jobs (approximately RM1,900), were retired (approximately RM1,500) or were not working (RM1,200) were relatively low. This illness may cause some of the respondents to fall into poverty, a process that has been referred to as "the medical poverty trap" (Whitehead, Dahlgren and Evans, 2001).

The financial burden resulting from extra medical and non-medical expenses and loss of income has caused financial difficulties for some of the respondents. Some respondents who owned properties were forced to sell them. A few respondents also used up their bank savings and their EPF. Some respondents had to borrow money from relatives, banks and associations. The severity of the financial burden was highlighted by a few respondents who reported difficulties in paying their bills.

The difference in reported treatment expenses between insured and non-insured respondents warrants further exploration to ensure that the differences are justified. Healthcare in Malaysia may be undergoing changes in the future, where the financing of healthcare would change from a taxation-based healthcare system to a social health insurance-based system, and the insurance sector will be required to play a much larger role (Chee, 2008). It is essential that all parties involved in healthcare must be responsible in their roles to ensure that health care costs do not spiral out of control and to ensure that any new financial model will result in a more equitable situation (Chai, Whynes and Sach, 2008).

Despite the adverse economic impacts, the respondents appeared to have coped relatively well socially. They claimed to have adequate support from family and friends. However, the number of respondents who joined cancer support groups was surprisingly low, and some claimed that they were not aware of such support groups. Breast cancer support groups in Malaysia, such as Breast Cancer Welfare Association, National Cancer Society of Malaysia, the National Cancer Council

(MAKNA), Cancer Link and Rotary Clubs should be made easily accessible to all patients.

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NOTES

1. Zakat is similar to tithes [payment to support a religious organization] except that in the Muslim faith it is considered to be obligatory. The money/ assets collected can be given to or used by certain categories of recipients which include the poor or people who cannot meet their basic needs.

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