SPECIAL ARTICLE

Household costs of breast cancer morbidity: An empirical assessment from Pakistan

Hafiz Zahid Mahmood[1], Imran Hameed Khaliq[2]*, Zafar Iqbal Bhatti[3], Kimberly J. Wilson[4], Khalid Masood Gondal[5], Summaira Malik[1], Shakila Zaman[2]

[1]Department of Economics, COMSATS University Islamabad, Lahore Campus, Pakistan; [2]Department of Public Health, University of Health Sciences Lahore, Pakistan; [3]Department of Pediatrics, Niazi Medical & Dental College, Sargodha, Pakistan; [4]Independent Consultant, Texas, USA; [5]Vice Chancellor, King Edward Medical University/ Mayo Hospital, Lahore, Pakistan

Summary

Purpose: Health care costs attributable to breast cancer are substantial. In countries with high poverty, lack of public health infrastructure and low availability of health insurance, the economic burden of disease does not accrue solely to health care, but also on patients and their families. This study was conducted to explore the cost burden (i.e. direct medical costs, direct non-medical costs and indirect non-medical costs) incurred by breast cancer patients and their families over diagnosis and treatment.

Methods: Data was collected from 200 breast cancer patients at two hospitals in Lahore, provincial capital of Punjab, Pakistan, by employing purposive sampling technique.

Costs were aggregated into three categories and compared with each other as per their weightage.

Results: The study found that direct medical care (US$ 1262.18/Local currency (PKR) 129,717) is the largest expense, followed by direct non-medical (US$ 310.88/PKR 31,950) and indirect non-medical costs (US$ 273.38/PKR 28,096).

Conclusions: The results of this study provide rich insight into the financial burden borne by households of breast cancer patients and suggest policy implications.

Key words: breast neoplasms, cost of illness, direct service cost, noncommunicable diseases, Pakistan

Introduction

While all types of cancers contribute significantly to mortality, breast cancer is the largest cause of cancer mortality among women globally. In low and middle-income countries (LMICs), it accounts for 12.7% of deaths in females [1]. Moreover, 1.67 million new cases were diagnosed in 2012, making it the second most common cancer in the world affecting women [2]. Its incidence is expected to surpass 2 million in 2030 due to rapidly growing population in developing countries [3].

Approximately 25% of breast cancer cases are diagnosed in Asia. Due to population aging, abruptly changing life styles and westernization, it has become one of the major causes of death among the women of Pakistan where the prevalence rate is relatively high [3,4]. Approximately 90,000 new cases are diagnosed annually with 1 in 9 likely to develop it during their lives [5]. Its age-standardized incidence rate (50.3), age-standardized mortality rate (25.2) and percentage of 5 years prevalence (52.5), are higher than those for other cancers [2].

A number of studies have assessed the cost of illness (COI) and mortality costs of breast cancer on macro and micro levels in the Japan [6], Costa Rica and Mexico [7], Vietnam [8], Iran [9], Mexico [10], and Korea [11]. However, a dearth of literature in developing countries exists regarding the cost of breast cancer for patients and their households.

Moreover, some studies report overall cost of illness (COI) of breast cancer but fail to provide detailed per capita expenditures.

Out-of-pocket (OOP) payment is the dominant mode of financing healthcare in developing countries [12] and is the primary payment mechanism for healthcare expenses in Pakistan [13] accounting for 54.9% of total expenditures on health [14]. This is problematic in a country where 29.5% (i.e. 60 million people) live below the poverty line [15].

Cancer diagnosis and treatment is a challenging task in LMICs [16]. Due to the absence of government support in Pakistan, healthcare expenditures surpass the average monthly household income for the majority of breast, brain and neck cancer patients [17]. Zaidi et al. found that while mean and median monthly income of patients in the study were US$996 and US$562, respectively, the mean and median monthly cost of cancer care were US$1,093 and US$946 [17]. In addition, 94% of families in this study reported bearing the cost of cancer treatment either fully or partially and viewed the financial burden of cancer as significant (42%) or unmanageable (18%).

Given the high prevalence and incidence of breast cancer and the lack of public infrastructure supporting diagnosis and treatment in developing countries like Pakistan, it is important to understand the costs of breast cancer borne by patients and their families. The objectives of this study were to investigate the direct medical, direct non-medical and indirect non-medical costs borne by patients' households from diagnosis through treatment following the framework suggested by the World Health organization [18]; a) to explore the sources of financing (i.e. savings, sale of assets, borrowing and financial support) used to pay for diagnosis and treatment; and b) to quantify the share of costs covered by health insurance in this study population.

Methods

The study was conducted in Lahore, the provincial capital of Punjab, Pakistan. Participants were recruited from two tertiary care public facilities, Jinnah and Mayo Hospitals, which serve the majority of patients in Punjab.

The following inclusion criteria were utilized in recruitment of study participants. Patients were eligible for inclusion if they were (1) female; (2) 18 years of age or older; (3) had been in treatment for 3 months to 2 years since diagnosis; (4) were diagnosed with metastatic breast cancer with any stage; (5) fluent in Urdu, English or regional languages i.e. Punjabi and Saraiki; and (6) able to provide informed consent. The time interval in the inclusion criteria was selected because it was close enough in time for breast cancer patients to have a comprehensive recall of their experiences [18,19].

Purposive sampling was employed with a goal of recruiting 200 breast cancer patients. A physician reviewed medical records to identify the patients who met the inclusion criteria. Prior to the data collection, an introductory brochure written in Urdu was provided to patients that described the study. All participants in the study provided written informed consent. Patients who were unable to sign their name provided consent by making a thumb impression, which witnessed (preferably patient attendant).

Data collection

Data was collected between August and December 2015. The primary focus of this study was on the costs of illness burden borne by the households of breast cancer patients. Three cost categories were included to quantify the financial burden of breast cancer morbidity: (a) Direct Medical, (b) Direct Non-Medical and (c) Indirect Non-Medical Costs. The research team developed items based on input from focus group discussions with 10 breast cancer patients and discussions with oncologists from the targeted hospitals. A semi-structured questionnaire was drafted and used as data collection instrument following guidelines of European Organization for Research and Treatment of Cancer (EORTC) [20]. The survey instrument was further pre-tested on 10 breast cancer patients under treatment in Jinnah Hospital, to assess presentation, face validity, acceptability and ease of understanding of the questions.

Direct medical costs include spending on diagnostic procedures, treatment, follow-up appointments with healthcare specialists, prescriptions, hospital in-patient and out-patient visits. *Direct non-medical costs* are those incurred by patients during the course of diagnosis and treatment that are not spent on treatment but rather incurred on travelling from home to health facility, overnight accommodations, meals in the destination city during diagnosis and treatment. *Indirect non-medical costs* relate to morbidity-related losses in income from time taken off work by the patient and her attendants. The measurement of indirect cost is primarily based on an output-related approach [21]. Productive work is broadly defined as involvement in any economic activity with the potential to add in disposable income to the households. This method does not include time loss of economically inactive persons such as a homemaker and job seekers. Both full and partial disability days were taken into account in this study. The valuation of indirect cost was based on the actual loss of income attributable to illness. Respondents were asked to state whether there was any form of income loss, and if so how much. This could either have been as a result of direct monetary loss, e.g. loss of daily wage of a casual laborer, or as a reduction in income due to loss in job income (salaries deductions)/business income. The costs of other household members covering the work of patients or patient caregivers were not included. In addition, this cost category also included other expenses incurred by the family as a result of the family member's cancer diagnosis, such

as additional educational services (i.e. tuition services) for children and the hiring of in-house help. Finally, *Total Cost of Illness* was derived by summing the totals of the three cost categories.

Apart from the aforesaid categories of costs of illness data the interview also collected information regarding the sources of financing (i.e. savings, sale of assets, borrowing and financial support) used to cover medical expenses and on the share of costs covered by health insurance.

Interviews ranged from 30 to 40 min and were conducted in the respondent's preferred language - Saraiki, Urdu or Punjabi. Costs were quantified in Pakistani Rupees and later converted into US dollars.

Statistics

Descriptive statistics i.e. frequency distributions, means, medians and percentages were the primary analytical methods used. Shapiro-Wilk test was run to inform decisions about whether to run parametric or non-parametric tests. The Spearman rank-order correlation coefficient was run to determine the strength and direction of association of three cost categories (i.e. direct medical cost, direct non-medical costs and indirect non-medical cost) with patients' age, patients' education, patients' husband education, family size, monthly house-

hold's income, patients' occupation immediately before breast cancer diagnosis and stages of breast cancer. Finally, the Mann-Whitney U test was used to compare the differences of two independent group variables (i.e. marital status and family history of breast cancer) with target cost categories. All analyses were run using the SPSS 22.0.

The study was approved by the Institutional Review Board of the King Edward Medical University, Lahore (No. 348/RC/KEMU).

Results

The average age and education of the study participants (n=200) was 43.87 and 4.64 years, respectively. Moreover, households had 3.82 children and patients' husbands had 7.21 years of schooling on average. Households had a mean size of 7.93 persons and average monthly income of US$229.17. Few households (4 out of 200) had no source of income other than support from relatives, neighbors and friends. Patients reported having symptoms of breast cancer for 13.5 months prior to diagnosis. Consequently, cancer was generally fairly advanced by the time it was diagnosed (54% in stage III and

Table 1. Cost of Illness (n=200)

Cost of Illness	Mean	Minimum	Maximum	SD	Median
Direct medical costs					
Diagnosis-related	2.98	0.00	97.30	11.43	0.09
General Practitioner	0.02	0.00	4.87	0.34	0.00
Expedited Care	0.11	0.00	15.57	1.16	0.00
Consultants	11.06	0.00	1138.47	82.88	0.05
Radiotherapy	13.58	0.00	2627.18	185.76	0.00
Chemotherapy	369.74	0.00	3892.12	545.32	109.47
Injections	239.43	0.00	7297.73	960.01	0.00
Surgery	230.63	0.00	1751.46	339.93	131.36
Prescriptions	148.10	0.00	1946.06	268.30	62.76
Medication, OTC	0.09	0.00	19.46	1.37	0.00
Lab Tests	246.41	0.00	821.23	161.14	221.27
Total	1262.18	0.00	11681.33	1593.39	778.24
Direct non-medical costs					
Travel expenses	297.46	0.00	1819.60	292.69	204.34
Overnight accommodation	13.42	0.00	486.52	54.56	0.00
Total	310.88	0.00	2014.21	300.40	214.85
Indirect non-medical costs					
Amount paid for home help taken	19.33	0.00	700.58	80.55	0.00
Amount paid for children's tuition services taken	2.35	0.00	340.56	24.59	0.00
Lost business income (Caregiver)	18.11	0.00	583.82	76.21	0.00
Lost job income (Caregiver)	76.64	0.00	2919.09	256.91	0.00
Lost business income (Patient)	60.75	0.00	3502.91	331.11	0.00
Lost job income (Patient)	96.20	0.00	1751.46	312.06	0.00
Total	273.38	0.00	3502.91	520.39	77.84
Total cost of illness	1846.44	0.00	11783.50	1733.23	1374.21

28% in stage IV). One in five participants reported family history of breast cancer and patients had been in treatment on average 8.6 months at the time of the survey (range: 3-24 months, SD= 6.6).

Financial resources for diagnosis and treatment

Self-financing of diagnosis and treatment expenses was the primary method of payment; a small minority (4%) received additional financial support from the government. Savings, sale of assets and earned income were used to pay for breast cancer treatment. Specifically, the vast majority (92.5%) drew from earned income to pay treatment expenses; 42% utilized their savings; and 41.5% sold assets.

Direct medical costs

Direct medical expenses contribute the highest portion of financial burden over patient households as shown in Table 1. Main contributors to this category were chemotherapy, injections, surgery, prescriptions, and laboratory tests (e.g. biopsy, computed tomography, estrogen and progesterone receptor and complete blood count tests). Direct medical expenses were US$1262.18 on average and ranged from US$31 to US$11,681. Expenses related to chemotherapy emerged as almost one fourth (23.2%) of the total direct medical costs (mean: US$370). Injections and surgery were major cost elements with an estimated amount of US$239 and US$230, respectively. Total spending on over the counter medicines was nominal (US$ 0.09) as were expenditures on radiotherapy (US$14).

Though the hospitals from which patients were sampled had the capacity to run laboratory tests at a nominal charge (or free), total OOP spending in this area was still US$246, on average. Reported reasons for avoiding the public hospital laboratories included: a) delays in getting test results (47.5%), b) inconvenient locations (33.5%), c) quality issues with test reports (30%), and d) recurring issues with test equipment (13.5%). Moreover, direct medical costs were significantly associated with patients' education (r_s=0.236, p=0.001), patients' husband education (r_s=0.357, p=0.001); and monthly households' income (r_s=0.407, p=0.001).

Direct non-medical costs

The primary direct non-medical cost incurred by patients and their families was travel costs related to various aspects of diagnosis and treatment. Because Lahore is one of few cities in Punjab, the majority of breast cancer diagnosis and treatment facilities are located there. Expenses related to travel are substantial and are positively correlated

(r_s=0.826, p=0.001) with distance of the household from the facility. Moreover, direct non-medical costs were significantly associated with patients' age (r_s=-0.182, p=0.010), and difference between categories of marital status (U=1771.0, p=0.004); and geographical location (U=2660.0, p=0.001) were also significant.

Indirect non-medical costs

Loss of patient and primary caregiver employment income were the two largest indirect non-medical costs, US$96.20 and US$76.64, respectively, followed by loss in patient business income (mean:US$60.75). The majority of households (95.5%) availed themselves of unpaid help; thus, average spending on paid home help was only US$19.33. Loss of primary caregiver business income amounted to US$18.11. Indirect non-medical costs were significantly associated with patients' age (r_s=-0.246, p=0.001), patients' husband education (r_s=-0.170, p=0.025); and patients' occupation before breast cancer diagnosis (r_s=-0.526, p=0.001).

Total cost of illness

Total cost of illness amounted to US$1,846.44 on average (range:168.58-11783.50, SD:1733.23).

Discussion

In this survey of patients recently diagnosed with breast cancer in Punjab province of Pakistan, direct medical expenses were the largest component of total cost of illness with indirect medical and non-medical expenses being similar. Patient households spent $1262.18, $310.88 and $273.38 on direct medical, direct non-medical and indirect medical costs, respectively, totaling $1846.44, a huge amount in a country where monthly household income averages US$268.10 [22]. In addition, none of the study participants reported having health insurance that could be used to cover some of the costs of diagnosis and treatment. According to Centre for Development Research, most residents of developing countries do not have access to health insurance [23]. Moreover, despite being treated in a public hospital, only 4% reported receiving any public assistance with covering medical expense.

In this study, we found that higher levels of education and income was associated with great spending on direct medical costs, which may indicate better medical treatment. Moreover, the majority of study participants were diagnosed in later stages of breast cancer. As about half were illiterate, this could be an indicator of low health

literacy but could also be due to general low access to health care, cultural norms or a combination of the three.

Approximately half of all Pakistanis live in poverty [24]. In instances, like the current study, where insurance and public assistance are largely unavailable, patients must sell assets, use limited savings, borrow from relatives and friends, and/or seek loans from informal sources to pay treatment-related expenses. In addition, for those living in rural areas, the frequent visits for chemotherapy, radiation and monitoring can make travel expenses especially cumbersome. Finally, breast cancer morbidity has serious effects on life routines including reduced energy for childcare, lower work productivity and lost income [25,26]. Thus, in addition to direct medical expenses, a diagnosis of breast cancer also results in significant indirect costs that may have lasting effects on household financial well-being.

While this study provides new insight into breast cancer diagnosis and treatment-related expenses in Pakistan, and how they are covered, it does have some limitations. First, due to resource limitations, only patients of the public sector tertiary care hospitals in Lahore were surveyed. The experiences of patients in private hospitals or other cities may differ, as may those of patients at Shaukat Khanum hospital, the only specialized cancer hospital in the country. Second, given that patients were surveyed less than a year after diagnosis, we were not able to ascertain the long-term impact of these expenses on patient households which, given the socioeconomic status of many at outset, is potentially substantial. Future studies should aim to better understand what lasting impact breast cancer has on household fiscal well-being. Finally, we were not able to assess whether greater spending on direct medical costs results in better outcomes nor the extent to which earlier diagnosis would reduce direct or indirect costs. Answering these two questions would greatly inform future policy on this topic.

In conclusion, the combination of direct and indirect expenses related to breast cancer diagnosis and treatment has significant financial consequences in the short-term on patient households. Given that the majority of patients were low-income at the outset, it is likely that the effects on household fiscal health are lasting. The Pakistan government should look for ways to reduce the financial burden borne by patients and their support networks whether through reducing expenditures, investing in initiatives aimed at earlier diagnosis, or expanding access to health insurance or public assistance for treatment. In so doing, it will ameliorate the short and long-term effects of breast cancer on patients and entire households.

Conflict of interests

The authors declare no conflict of interests.

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