

The Direct and Indirect Costs of Cancer among the Lower-Income Group: Estimates from a Pilot and Feasibility Study

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Abstract

Background: Healthcare in Malaysia is largely publicly funded, however, cancer could still result in out-of-pocket (OOP) expenses, which may burden the affected patients. This is especially relevant to those in the lower-income group. This pilot study was conducted to estimate the direct and indirect costs of cancer and evaluate the feasibility of obtaining these costs information from the lower-income cancer patients undergoing treatment. **Methods:** A cross-sectional study of patients with cancer was conducted in Hospital Kuala Lumpur between September and October 2020. Self-reported data from the patients were collected using face-to-face interviews. Detailed information about cancer-related OOP expenses including direct medical, direct non-medical, and productivity loss in addition to financial coping strategies were collected. Costs data were estimated and reported as average annual total costs per patient. **Results:** The mean total cost of cancer was estimated at MYR 7955.39 (US\$ 1893.46) per patient per year. The direct non-medical cost was the largest contributor to the annual cost, accounting for 46.1% of the total cost. This was followed by indirect costs and direct medical costs at 36.0% and 17.9% of the total annual costs, respectively. Supplemental food and transportation costs were the major contributors to the total non-medical costs. The most frequently used financial coping strategies were savings and financial support received from relatives and friends. **Conclusion:** This study showed that estimation of the total cost of cancer from the patient's perspective is feasible. Considering the significant impact of direct non-medical and indirect costs on the total costs, it is vital to conduct further exploration of its cost drivers and variations using a larger sample size.

Keywords: Cancer, direct medical cost- direct non-medical cost- indirect cost- lower-income group

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Introduction

Malaysia has a widespread and efficient healthcare system that operates a two-tier system consisting of a government-run universal healthcare system and the co-existing private healthcare system. The utilisation of public healthcare services is highly subsidised for all Malaysian citizens, with only nominal charges being levied on certain services that the patients must pay using out-of-pocket (OOP) payment (World Health Organization, 2012). Given that the charges imposed at government hospitals are heavily subsidised or very minimum, compared with private hospitals, 50% of cancer patients would still face a financial catastrophe one year after their diagnosis (ACTION Study Group, et al., 2015). Besides direct costs stemming from medical and non-medical costs, the financial burden also includes indirect costs due to loss of productivity, wages and

savings (McNulty and Khera, 2015). The financial burden which covers the direct medical, direct non-medical and indirect costs will be a growing concern to the affected cancer patients and their families.

Direct medical costs involve transactions for medical services, such as physician services, diagnostic tests, drugs and other medical supplies, and hospitalisation expenses. Non-medical expenses, on the other hand, constitute costs that are not involved in the direct purchasing of medical services, for example, expenditures for transportation, child or elderly care, housekeeping assistance, wigs, and others. Meanwhile, indirect costs are accumulated as a result of sickness or absence from work, with loss of income and productivity. This can be incurred by both the patient, and households providing care in the hospital and at home after discharge. Productivity costs, which are often overlooked in most cost estimations, can represent more than two-thirds of total disease burden costs

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(Jonsson and Wilking, 2007).

Besides a deeper understanding of the cancer costs, identifying patients who are at higher risk of experiencing financial catastrophe is also important (Carrera et al., 2018). A previous study has reported that OOP expenses potentially pose a heavier burden among those with lower-income status (Longo et al., 2006). Non-medical expenses in particular were demonstrated to be the biggest contributor to financial catastrophe in public hospitals, forming almost 71% of their total expenses, followed by medical (17%) and traditional medicine (13%) (ACTION Study Group, et al., 2015). Additionally, poor patients, especially those living in rural areas and having difficulties with transport are most likely not able to continue treatment due to financial constraints in paying for the transportation cost. They are particularly a socioeconomically disadvantaged group of people including the bottom 40% income group (B40), those with disabilities and senior citizens.

Cancer costs may have a significant impact on health and finance not only for an individual but also for a family or household. The impact will be more glaring for a household in the B40 group. The B40 group has been categorised as the lowest household income group in which they are measured as a unit that earns a household income of RM 4849 (\$1064.78) and below in the year 2019 (Department of Statistics Malaysia, 2020). This group, who generally have the lowest financial reserves will be at higher risk of experiencing financial burden once diagnosed with cancer. The research focused on the financial burden of cancer specifically on a lower-income group is not fully explored. Additionally, details on various costs incurred by patients are still lacking, which makes it difficult to gauge the financial needs of affected people. Thus, this study seeks to evaluate the feasibility of obtaining detail cost information from the lower-income group cancer patients and in parallel, estimated the direct and indirect costs of cancer. Building on the future large-scale study, it sets to improve on the methodology used by reflecting all the procedures that are to be included in the large-scale study. These include validating the study questionnaires, the recruitment of study participants, suitability of data to be collected for required analysis as well as estimating the sample size (In, 2017; Bengier et al., 2016).

Materials and Methods

Study design and setting

This pilot cross-sectional study was conducted in September and October 2020 at the Radiotherapy and Oncology Department, Hospital Kuala Lumpur (HKL). HKL is a publicly funded, tertiary referral hospital under the Ministry of Health (MOH) Malaysia. It serves the main populations of Kuala Lumpur and Selangor and is one of the radiotherapy and oncology centres under the MOH. The sample size was selected in accordance with a general flat rule for pilot feasibility studies (Lancaster et al., 2004; Browne, 1995).

Study participants

Those included in the study were cancer patients from low-income households attending the study site, diagnosed with any type of cancer, undergoing cancer treatment and declared to be on active cancer treatment. The low-income patient refers to the patient in the B40 group of the Malaysian household (B40) group with a median household income of below MYR 4849 (Department of Statistics Malaysia, 2020). Eligible patients who are on treatment, aged 40 years and above, and capable to respond to the interview were enrolled from the day-care chemotherapy unit, oncology ward, and oncology clinic. Aged 40 years and above was set as one of the criteria, which was based on the increasing trend of incidence rates for all cancers combined, being the older people, especially after the age of 40 years (Azizah et al., 2019). On the other hand, the critically ill patients who were unable to provide the required information and those on follow-up only were excluded from this study. Written informed consent was obtained from all eligible participants prior to the interview. Information was collected by trained team members via face-to-face interviews.

Data collection

The collection of data was undertaken with the aid of a data collection tool, a study questionnaire. The questionnaire consisted of 4 sections: (1) sociodemographic and clinical profiles; (2) direct costs; (3) indirect costs and (4) financial coping mechanisms, which were first pretested to friends and colleagues for cross-checking and improving the overall style and structure of the study instrument prior to interview. Questions on sociodemographic and direct costs were self-developed and questions on indirect costs were adapted from the iMTA Productivity Cost Questionnaire (Bouwman et al., 2015). Questions on financial coping mechanisms were adapted from the National and Health Morbidity Survey 2019 (Institute for Health Systems Research, 2020). This study tool was used to collect all cost data required for the analysis. Researchers involved received training on interview-based methodologies and data collection prior to the interview. The primary resource report by the patients will be by the recollection of the previous three months for direct costs and four weeks for indirect costs. As the study participants were undergoing cancer treatment at the time of the study, we could only estimate the past and present expenses. This study was not designed to follow up with the study participants, thus, it missed the information on expenditure beyond the interview date.

Costing Components and Measurements

The cost data collected for this study included cancer-related expenses by patients using their OOP payments. All data obtained were annualised to estimate the annual total cost per patient.

1. Direct Costs. Direct medical costs were defined as self-reported costs incurred for medical care. Hospital charges consisted of three components: inpatient cost, outpatient cost and purchased medical supplies. Direct non-medical costs included the costs of transportation and costs associated with lodging, meal expenditure, childcare,

supplemental foods and other alternative treatments. For patients using their transportation, the cost was calculated based on fuel consumption over the travel distance from their residence to the treatment site (MYR 0.50/km). For other means of transport, the value was based on the transport fee reported by patients multiplied by the number of trips.

2. Indirect Costs. Indirect cost is defined as the productivity loss of cancer patients due to short-term and long-term inability to work. Productivity losses are calculated due to absenteeism (employed) and inability to do care work (unemployed including housewives, retirees, and elderly) were included. Details on employment, earnings, and time off from work or inability to do household work due to pain during the last four weeks from the interview day were collected. For employed patients, productivity loss was calculated by multiplying daily wage with days of work missed. The daily wage was calculated by dividing the self-reported monthly income by 26, as it was assumed that wage-earners worked a six-day week. The productivity loss for unemployed patients was calculated by using the national minimum monthly wage in 2016 (National Wages Consultative Council, 2016) for Peninsular Malaysia, which corresponds to MYR 1000.00. Productivity loss for the elderly aged 60 years was calculated based on the term care work which includes direct (reading to a child, giving medicine to the sick) and indirect (cooking, laundry, cleaning, gardening) forms of care (Choong et al., 2019). Based on the term care work, the elderly spend around 6 hours per day doing their productive activities (Universiti Putra Malaysia, 2018).

3. Financial coping mechanisms. These include any means of income obtained from household members, non-household members, relatives or friends, savings, and other financial sources which are non-refundable. Income derived from selling household assets such as jewellery, property, land and any household items; individuals or institutions' borrowings could also be sources of finance to support cancer-related expenses.

End points and statistical analysis

The main end point of this study was costs-associated with cancer, which was analysed using SPSS statistical software package version 26.0 (SPSS Inc., Chicago, Illinois, USA). Descriptive statistics were reported either in mean (\pm standard deviation, SD) or median (interquartile range, IQR) for continuous variables. Categorical variables were reported in frequencies (percentage, %) while cost data were reported in both mean and median. Of the 40 reported participants, one extreme outlier was observed from the total costs, thus it was removed from further analyses. All cost data are presented in Malaysian Ringgit (MYR). In parallel, the other end point was feasibility, measured as the number of patients who were able to provide detailed cost information of their cancer-related treatments that are required for study analysis.

Ethical Approval

This study was approved by the Medical Research Ethics Committee (MREC) Ministry of Health Malaysia

with approval number: KKM/NIHSEC/P20-1349 (6). Site approval was also obtained from the Clinical Research Centre Hospital Kuala Lumpur (CRC HKL) prior to the data collection with reference number: HCRC.IIR-2020-08-156.

Results

Sociodemographic and clinical profiles

Of the 43 relevant participants approached, 40 participants aged 40 years and above were interviewed face-to-face resulting 93% response rate. Their sociodemographic and clinical profiles are presented in Table 1. Most of the participants belong to the age group 65-74 years (40.0%). The mean age of the patients was 63.1(8.6) years. There were 26 (65.0%) male and 14 (35.0%) female participants. Both Malay and Chinese ethnicity constituted the majority group in the study sample with approximately 42.5% each. A majority had at least secondary level education, were married and unemployed. About 44.8% reported unemployment due to cancer. Regarding cancer diagnosis, 35.0% of participants were diagnosed with gastrointestinal cancers, 27.5% had breast cancer, and 12.5% had urogenital cancers. The majority of the study participants (76.9%) had been diagnosed with cancer for more than 6 months. Regarding present treatment, the majority of the study participants (51.3%) were receiving chemotherapy, and 10 (25.6%) were receiving radiotherapy at the time of the interview conducted. On average, these cancer patients made a total of 3 inpatient visits, and 16 outpatient visits and were hospitalised for 15 days, annually.

Total Costs incurred by cancer patients

Table 2 shows the total cost of cancer comprising direct medical, direct non-medical, and indirect costs. The median (IQR) and mean (SD) direct medical costs of cancer were MYR 458.00 (1382.00) and MYR 1423.54 (2398.32), respectively. Medical supplies contributed to 47.9% of the total medical costs while 33.0% and 19.1% contributed to inpatient and outpatient services. The median (IQR) and mean (SD) of the direct non-medical costs were MYR 1920.00 (2787.52) and MYR 3667.37 (6287.46), respectively. The highest direct non-medical cost was supplemental food (64.9%) followed by transportation (23.2%), and meals (9.7%), while other costs reported 2.2%. Employed individuals experienced missed workdays of around 51 days while unemployed participants experienced reduced home productivity of around 114 days annually. Collectively, the average loss of productivity was estimated at MYR 2864.49 (3319.31).

Direct non-medical cost plays the largest role in driving cancer patients' costs with 46.1%, while indirect and direct medical costs contributed around 36.0% and 17.9% of the total costs, respectively. Overall, average annual expenses incurred associated with cancer were estimated at MYR 7955.39 (8902.24).

Transportation cost

The average round-trip travel distances and costs by location from the treatment site are shown in

Table 1. Sociodemographic and Clinical Characteristics of Study Participants

Sociodemographic/ Clinical characteristics	Mean (SD)	Frequency (n)	Percentage (%)
Age (years), Mean (SD)		63.1 (8.6)	
40-54		6	15
55-64		15	37.5
65-74		16	40
≥75		3	7.5
Gender			
Male		26	65
Female		14	35
Ethnicity			
Malay		17	42.5
Chinese		17	42.5
Indian		5	12.5
Others		1	2.5
Education level			
No formal education		2	5
Primary level		15	37.5
Secondary level		23	57.5
Marital status			
Married		27	67.5
Not married		13	32.5
Employment status			
Public sector		0	0
Private sector		1	2.5
Self-employed		3	7.5
Unemployed		29	72.5
Retiree		7	17.5
Unemployment due to cancer (n=29)			
Yes		13	44.8
No		16	55.2
Monthly income (MYR)			
<MYR 1000		28	70
MYR 1001-2000		8	20
>MYR 2000		4	10
Diagnosis (by cancer site)			
Gastrointestinal		14	35
Breast		11	27.5
Urogenital		5	12.5
Respiratory		2	5
Female reproductive		2	5
Others		6	15
Duration of diagnosis			
< 6 months		9	23.1
6 months and above		31	76.9
Present treatment			
Chemotherapy		21	51.3
Radiotherapy		10	25.6
Surgery		1	2.6
Others*		8	20.5
Annual inpatient visits	2.93 (2.65)		
Annual admission days	14.85 (14.88)		
Annual outpatient visits	15.80 (15.82)		

*Includes treatment other than chemotherapy, radiotherapy and surgery

Table 3. Average round-trip travel distances and annual transportation costs among those living within the Klang Valley area (refers to the central region which includes Selangor, federal territories of Kuala Lumpur and Putrajaya) were estimated at 16.6 km and MYR 372, respectively. While those living outside the Klang Valley area travelled longer at an average round-trip of 231.55 km to reach the treatment site and spent MYR 1632.28 per year on transportation.

Financial coping strategies

Various coping strategies were used by the study participants to pay for their cancer-related expenses. The majority of participants had used their household savings (76.9%) for cancer-related payments. A considerable percentage (64.1%) of participants have received financial sources and support from their relatives and friends to cover the financial burden imposed due to having cancer. The remaining expenses were covered by selling assets (10.3%) and received financial support from non-governmental organizations and social welfare centres (25.6%). However, none of the study participants had either used health insurance or taken loans to pay for their cancer-related expenses, as illustrated in Figure 1.

Discussion

This pilot and feasibility study estimated the cancer costs from the perspective of patients and reflect a significant financial burden among the study participants. Indeed, the annual total costs was estimated at MYR 7955.39 per individual with cancer. The largest contributor to cancer-related costs was direct non-medical cost (average MYR 3667.37; 46.1% of the total costs of cancer), over half of which were attributed to supplemental food and transportation. Not surprisingly, the direct medical cost was the least contributor to the financial burden of cancer being the treatment sought at public hospitals is primarily subsidised by the Malaysian healthcare system. However, patients were reported to be financially impacted by buying medical supplies such as breast prostheses, stoma bags, diapers, needles, syringes, and others as these items are not subsidized by the government. Medical supplies alone contribute to 47.9% of the total direct medical cost, equivalent to MYR 682.55 per individual with cancer.

Given a large fraction of the total costs (46.1%), this study reported that direct non-medical cost plays the largest role in driving patients' costs. Of these, the cost of supplemental food was the highest. This is in agreement with a study conducted by Yen et al., (2015), in which supplements including fortified milk, multivitamins, etc contribute most (45%) to the direct non-medical cost. Besides supplemental food, transportation costs represent one of the main cost components in the non-medical cost category (Bona et al., 2021; Kong et al., 2020; Barwal et al., 2019; Zucca et al., 2011), which can be a barrier to accessing healthcare services. This is especially true for those in lower-income groups who live far away from the treatment sites. This is the likely reason for the substantial transportation cost reported in this study, whereby patients

Table 2. Total Costs and Their Components

Costs (MYR)	Median (IQR)	Mean (SD)	% of total costs
Direct medical costs	458.00 (1382.00)	1423.54 (2398.32)	17.9
Inpatient care	125.00 (370.00)	469.71 (1021.72)	33
Outpatient care	20.00 (284.00)	271.28 (526.48)	19.1
Medical supplies ^a	0.00 (48.00)	682.55 (1770.78)	47.9
Direct non-medical costs	1920.00 (2787.52)	3667.37 (6287.46)	46.1
Place to stay	0	30.77 (192.15)	0.8
Transportation ^b	448.00 (1286.4)	849.44 (936.61)	23.2
Meal	120.00 (480.00)	354.05 (539.02)	9.7
Childcare	0	33.33 (165.96)	0.9
Supplemental food	0.00 (2040.00)	2380.24 (6073.78)	64.9
Alternative treatment	0	5.13 (32.03)	0.1
Others	0	14.41 (48.44)	0.4
Indirect costs	1385.28 (5999.76)	2864.49 (3319.31)	36.0
Missed productive days at work ^c		51.00 (59.09)	
Reduced productive days at home ^d		114.51 (133.73)	
Missed productive days	48.00 (240.00)	108.00 (129.07)	
Total Costs	5858.84 (6555.24)	7955.39 (8902.24)	100

^a Medical supplies constituted of equipment and/or disposable items (e.g., breast prosthesis, stoma bag, diapers, needles, syringe, etc.); ^b Transportation includes fuel (mileage/km), toll, parking fees and public transport fees; ^c Absent from work (employed); ^d Absent from work (employed); All values are reported in MYR.

Table 3. Transportation Distance (km/ journey) and Annual Transportation Cost of Patients

Transportation	n (%)	Median (IQR)	Mean (SD)
Round-trip travel			
Distance (km)			
Within Klang Valley	29 (74.4)	27.30 (21.48)	16.60 (28.25)
Outside Klang Valley	10 (25.6)	250.50 (106.25)	231.55 (157.95)
Annual Cost			
Within Klang Valley	29 (74.4)	565.78 (674.85)	372.00 (579.20)
Outside Klang Valley	10 (25.6)	1672.07 (1129.56)	1632.28 (1759.38)

All values are reported in MYR. Klang Valley refers to central region which includes Selangor and the Federal Territories of Kuala Lumpur and Putrajaya.

from outside Klang Valley areas spent almost four times that of patients who reside in the Klang Valley areas. Kong et al., (2020) also reported that transportation costs to the hospital for treatment and follow-up visits were frequently reported as a burden by participants from lower socioeconomic status.

Estimation of indirect costs reflects the real changes in productivity due to disease, including short-term absence from work, limitation in household chores, time spent in bed and income lost (Altice et al., 2016; Dowling et al., 2013). Studies focusing only on direct costs do not fully account for the financial burden due to cancer, as indirect costs are related to productivity loss. Although the majority of the study participants were unemployed and had no consequences on their income, their productivity loss was measured through the time loss from being physically active. Indeed, the magnitude of the indirect cost of unemployment suggests a burden on the household members, however, this study did not capture the time loss of the family members. In this analysis, the indirect cost amounts to about one-third of the total cost (36%),

a substantial burden estimated at MYR 2864.49 per individual. Other studies also reported that the indirect cost is half of the total costs, which is essential to address the cost incurred by cancer patients and not covered by insurance (Singleterry, 2017). In Sweden, indirect costs (missed work hours) made up to 50% of the total costs for patients aged below 65 years (Lindgren et al., 2007), while in a study conducted among Australian breast cancer patients, the indirect cost was responsible for more than 60% of the total costs (Gordon et al., 2007).

When asked about the financial coping strategies after being diagnosed with cancer, the study findings showed that most cancer patients used more than one coping strategy. Similar to a study conducted by Chakbarty et al., (2017), multiple coping strategies were used by the patients and their families, with the most prevalent being spending savings, selling assets, borrowing and other financial support. Among those, saving was the primary financial coping strategy used in this study, which was also reported by several studies (Tolla et al., 2017; Azzani et al., 2016; Engalgau et al., 2012; Bogale et al., 2005). A

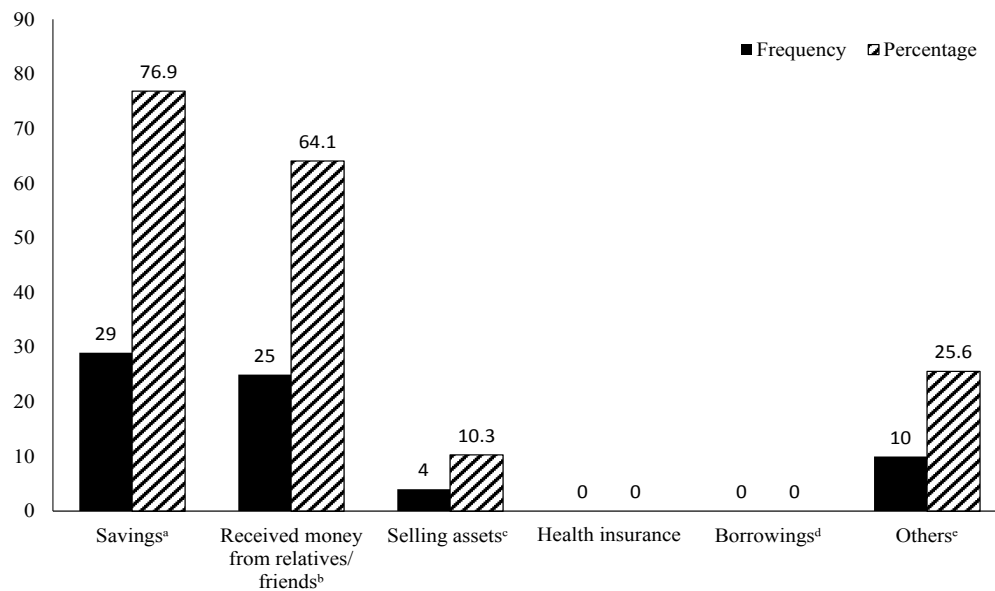


Figure 1. Financial Coping Strategies Used by Cancer Patients, n (%). Note, Frequencies and percentages would not be added up because multiple responses were possible; ^a It includes personal and household savings (i.e., Employee’s Provident Fund, EPF); ^b Financial support received from relatives and friends which are non-refundable; ^c Any means of selling household assets like jewellery, property, land and other household items; ^d Borrowings or taking loans from individuals and financial institutions; ^e Other financial sources received from non-governmental organizations (i.e., MAKNA) and social welfare centres (i.e., Zakat).

study conducted in Pakistan by Zaidi et al., (2012) also reported that 34.3% of cancer patients used their savings until they fell into debt. Notably, some other studies reported that selling assets and borrowings were the major coping strategies (Bogale et al., 2005; Pourreza et al., 2017; Kruk et al., 2009; Leive et al., 2008). Azzani et al., (2016) also reported an increase in the percentage of households of colorectal cancer patients selling household items or borrowing money from relatives and friends to cope with their new financial situation.

The financial burden arising from cancer-related costs among patients from lower-income households highlights the need for these patients to be navigated to appropriate social welfare schemes and financial aid. Inadequate funds for cancer care may disrupt patient continuation in seeking treatment at hospitals. An initiative by the government through a programme such as the Skim Peduli Kesihatan for the B40 group (PeKa B40) will be able to pave the way and help the vulnerable B40 group living with cancer accelerate their access to definitive therapy. The cancer patients could benefit from the MYR 1000 of the Completing Cancer Treatment Incentive (CCTI) and up to MYR 500 of the transport incentive (ProtectHealth Corporation, 2021).

Nonetheless, this pilot study is subject to a number of limitations. Cancer-related costs were calculated from the patient’s perspective, by which costs incurred by the cancer patients were considered. Moreover, all information collected in this study was self-reported, which may lead to recall bias such as exaggeration and selective memory. A more general limitation of this study is that it focuses on patients seeking treatment at government hospitals, excluding those who seek treatment at private facilities. It is worth mentioning that zero value was

recorded in some of the cost components which creates large variability in the cost analysis conducted. Zero value was recorded for medical supplies, especially in patients who received assistance from non-governmental organizations (NGOs) such as the National Cancer Council (MAKNA). Similarly, zero value under non-medical costs was observed for accommodation and childcare as some patients arranged lodging with relatives and had family members or neighbours to look after their children. Some of the interviewed patients also had no expenditure on supplemental food and alternative treatments, either due to unavailable funds or claimed not needed. Finally, being a pilot study, the small sample size was utilised and only those in the lower-income group were accounted for, thus, the analysis may not be generalisable to greater Malaysian populations.

From the feasibility outcome’s point of view, this study evaluated the overall study procedure in terms of the patient’s ability to understand the questions and recall information, the patient’s ability to complete the interview, and the duration to complete each interview. Costs data gathered required for data analysis was also achieved. Despite positive participation from the cancer patients, the main issue was observed while conducting the interview which relates to identifying the targeted cancer patients, those in the lower income group. This has brought us a challenge due to insufficient patient information. To address this issue, the involvement of the person in charge of each study site eventually eased the search and recruitment of the study participants by identifying those eligible patients. These findings are encouraging and suggest proceeding with a large-scale study covering a more representative sample across regions.

In conclusion, this pilot study provides insights into

the detail cost information collected from the perspective of cancer patients who are engaged in the active treatment process, thus, evaluation of the cancer-related costs is feasible. The direct and indirect costs associated with cancer treatment had substantial financial implications on patients and possibly their household members. Considering the potentially significant impact that these costs can have on the affected patients, this study is valuable in providing informative data to stakeholders and policymakers for future financial planning. The financial impact resulting from cancer-related expenditures may cause financial difficulties for cancer patients especially those in the lower-income groups even in a country where healthcare is heavily subsidised by the government. We believe that financial incentives such as the PeKa B40 serve as one of the government's efforts to address the growing burden of cancer, equipping patients with means and assistance as part of cancer treatment processes.

Author Contribution Statement

Conceptualization, F.A. and N.Z.A.M.H.; methodology, F.A and M.S.B.; validation, N.A.Z., A.N.M.H and N.Z.A.M.H.; formal analysis, F.A., M.S.B. and N.Z.A.M.H.; investigation, F.A., M.S.B. and N.A.Z.; resources, M.S.B., N.A.Z. and A.N.M.H.; data curation, F.A. and M.S.B.; writing—original draft preparation, F.A.; writing—review and editing, M.S.B., N.A.Z., A.N.M.H. and N.Z.A.M.H.; supervision, N.Z.A.M.H.; funding acquisition, F.A. All authors have read and agreed to the published version of the manuscript.

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Ethical Approval

The study was conducted in accordance with the Declaration of Helsinki and approved by the Medical Research Ethics Committee (MREC) Ministry of Health Malaysia. Besides, site approval was obtained from the Clinical Research Centre Hospital Kuala Lumpur (CRC HKL) prior to the data collection. (Ref: KKM/NIHSEC/P20-1349 (6) and HCRC.IIR-2020-08-156).

Informed Consent Statement

Written consent was obtained from study participants before the beginning of the interview. To ensure

participants' confidentiality, questionnaires were coded to prevent any identification and stored in the lockable cabinet except for access to the study team.

Data Availability

The data presented in this study are available on request from the corresponding author.

Conflict of Interest

The authors declare no conflict of interest.

References

- ACTION Study Group, Kimman M, Jan S, et al (2015). Catastrophic health expenditure and 12-month mortality associated with cancer in Southeast Asia: results from a longitudinal study in eight countries. *BMC Med*, **13**, 190.
- Altice CK, Banegas MP, Tucker-Seeley RD, et al (2016). Financial hardships experienced by cancer survivors: A systematic review. *J Natl Cancer Inst*, **109**, djw205.
- Azizah AM, Hashimah B, Nirmal K et al (2019). Malaysia National Cancer Registry Report (MNCR) 2012-2016, 5.
- Azzani M, Roslani AC, Su TT (2016). Financial burden of colorectal cancer treatment among patients and their families in a middle-income country. *Support Care Cancer*, **24**, 4423-32.
- Barwal VK, Thakur A, Mazta SR, et al (2019). Out-of-pocket expenditure for diagnosis of lung cancer: a significant pretreatment financial burden- study from a tertiary care cancer center in North India. *CHRISMED J Health Res*, **6**, 18-22.
- Benger J, Coates D, Davies S, et al (2016). Randomised comparison of the effectiveness of the laryngeal mask airway supreme, i-gel and current practice in the initial airway management of out of hospital cardiac arrest: a feasibility study. *Br J Anaesth*, **116**, 262-8.
- Bogale T, Mariam DH, Ali A (2005). Costs of illness and coping strategies in a coffee-growing rural district of Ethiopia. *J Health Popul Nutr*, **23**, 192-9.
- Bona LG, Geleta D, Dulla D, et al (2021). Economic burden of cancer on cancer patients treated at Hawassa University comprehensive specialized hospital. *Cancer Control*, **28**, 10732748211009252.
- Bouwman C, Krol M, Severens H, et al (2015). The iMTA productivity cost questionnaire: A standardized instrument for measuring and valuing health-related productivity losses. *Value Health*, **18**, 753-8.
- Browne RH (1995). On the use of a pilot sample for sample size determination. *Stat Med*, **14**, 1933-40.
- Carrera PM, Kantarjian HM, Blinder VS (2018). The financial burden and distress of patients with cancer: Understanding and stepping-up action on the financial toxicity of cancer treatment. *CA Cancer J Clin*, **68**, 153-65.
- Chakrabarty J, Pai MS, Ranjith V, et al (2017). Economic burden of cancer in India. *Indian J Public Health*, **8**, 137-41.
- Choong C, Mohamed Firouz AM, Jasmin AF, et al (2019). Time to care: Gender inequality, unpaid care work and time use survey. Khazanah Research Institute.
- Department of Statistics, Malaysia (2020). Report of household income and basic amenities survey 2019, accessed November 29, 2021.
- Dowling EC, Chawla N, Forsythe LP, et al (2013). Lost productivity and burden of illness in cancer survivors with and without other chronic conditions. *Cancer*, **119**, 3393-401.
- Engelgau MM, Karan A, Mahal A (2012). The Economic impact

- of non-communicable diseases on households in India. *Global Health*, **8**, 9.
- Institute for Health Systems Research (IHSR), National Institutes of Health, Ministry of Health Malaysia (2020). National Health and morbidity Survey (NHMS) 2019: Vol. II: Healthcare Demand.
- Gordon L, Scuffham P, Hayes S, et al (2007). Exploring the economic impact of breast cancers during the 18 months following diagnosis. *Psychooncology*, **16**, 1130-9.
- In J (2007). Introduction of a pilot study. *Korean J Anesthesiol*, **70**, 601-5.
- Jonsson B, Wilking N (2007). The burden and cost of cancer. *Ann Oncol*, **18**, 8-22.
- Kong YC, Wong LP, Ng CW, et al (2020). Understanding the financial needs following diagnosis of breast cancer in a setting with Universal Health Coverage. *Oncologist*, **25**, 497-504.
- Kruk ME, Goldmann E, Galea S (2009). Borrowing and selling to pay for health care in low- and middle-income countries. *Health Aff (Millwood)*, **28**, 1056-66.
- Lancaster GA, Dodd S, Williamson PR (2004). Design and analysis of pilot studies: recommendations for good practice. *J Eval Clin Pract*, **10**, 307-12.
- Leive A, Xu K (2008). Coping with out-of-pocket health payments: empirical evidence from 15 African countries. *Bull World Health Organ*, **86**, 849-56.
- Lidgren M, Wilking N, Jönsson B, et al (2007). Resource use and costs associated with different states of breast cancer. *Int J Technol Assess Health Care*, **23**, 223-31.
- Longo CJ, Fitch M, Deber RB, et al (2006). Financial and family burden associated with cancer treatment in Ontario, Canada. *Support Care Cancer*, **14**, 1077-85.
- McNulty J, Khera N (2015). Financial hardship-an unwanted consequence of cancer treatment. *Curr Hematol Malig Rep*, **10**, 205-12.
- National Wages Consultative Council (2016). The National Minimum Wages 2016, Ministry of Human Resources Malaysia, accessed August 12, 2020.
- Pourreza A, Harirchi I, Bazzyar M (2017). Differentiation of out-of-pocket expenditures in cancer patients; a case study in the cancer institute of Iran. *Evid Based Health Policy Manage Econ*, **1**, 65-73.
- Razif IM, Abdul Jabar M, Ismail NA (2021). PeKa B40 Report 2021, accessed May 19, 2022.
- Singleterry J (2017). American Cancer Society Cancer Action Network. The costs of cancer: addressing patient costs. Washington: American Cancer Society Cancer Action Network.
- Tolla MT, Norheim OF, Verguet S, et al (2017). Out-of-pocket expenditures for prevention and treatment of cardiovascular disease in general and specialised cardiac hospitals in Addis Ababa, Ethiopia: a cross-sectional cohort study. *BMJ Glob Health*, **2**, e000280.
- Universiti Putra Malaysia (2018). Retirement Preparedness and Productive Ageing among Government Employees and Retirees in Klang Valley (Final Report).
- World Health Organization. (2012). Malaysia health system review. Health Systems in Transition. Asia Pacific Observatory on Health Systems and Policies, accessed January 10, 2022.
- Yen S, Abd Shatar A, Hashim H (2015). Exploring the economic impact on breast cancer patients in Kelantan. *Jurnal Perspektif Jil*, **7**, 43-56.
- Zaidi AA, Ansari TZ, Khan A (2012). The financial burden of cancer: estimates from patients undergoing cancer care in a tertiary care hospital. *Int J Equity Health*, **11**, 60.
- Zucca A, Boyes A, Newling G, et al (2011). Travelling all over the countryside: travel-related burden and financial difficulties reported by cancer patients in New South Wales and Victoria. *Aust J Rural Health*, **19**, 298-305.



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