

# **Faculty of Economics and Business**

The Burden of Illness in Cancer Survivors: An Economic Perspective

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# THE BURDEN OF ILLNESS IN CANCER SURVIVORS: AN ECONOMIC PERSPECTIVE

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This project is submitted in partial fulfilment of the requirements for the degree of Bachelor of Economics with Honours (Service Economics)

> Faculty of Economics and Business UNIVERSITI MALAYSIA SARAWAK 2020

# **Statement of Originality**

# The work described in this Final Year Project, entitled **"The Burden of Illness in Cancer Survivors: An Economic Perspective"**

is to the best of author's knowledge that of the author except where due to reference is made.

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# ABSTRACT BURDEN OF ILLNESS IN CANCER SURVIVORS: AN ECONOMIC

# PERSPECTIVE

#### By

## Siew Ke Lin

The main objective of this study was to study the "Burden of Illness in Cancer Survivors: An Economic Perspective". Cancer is a prevalent illness and leading cause of death in Malaysia today. The death rate and prevalence of cancer has risen year by year and the economic consequences of the disease are a burden to patients and their families. A cancer patient may find it difficult to afford expensive cancer treatment. Thus, a face to face interview was conducted in the Department of Radiotherapy, Oncology and Palliative Care Unit in Sarawak General Hospital to better understand the economic burden of cancer on patients. In the results, cancer care costs have been calculated for various socioeconomic factors and clinical profiles. In addition, the cancer survivors suffered from financial burdens in terms of financial costs and loss of productivity in terms of absenteeism and presenteeism. The approximate cost of cancer medical treatment was highly predicted and statistically differences among age group, level of education, cancer stages and pathway of treatment. In view of the growing number of cancer survivors, it is critical that policymakers or providers develop protection strategic for tackling this problem. Prioritizing cancer as a major health concern would certainly improve the survival rate and reduce the financial burden of cancer.

Keywords: Financial costs, financial toxicity, work productivity

# ABSTRAK BEBAN PESAKIT KANSER: DARI PERSPEKTIF EKONOMI

#### Oleh

## Siew Ke Lin

Objektif utama kajian ini adalah untuk mengkaji "Beban Pesakit Kanser: Dari Perspektif Ekonomi". Kanser adalah penyakit kronik dan penyebab utama kematian rakyat Malaysia hari ini. Kadar kematian dan prevelensi kanser meningkat dari semasa ke semasa dan membebankan pesakit dan keluarga mereka. Seseorang pesakit kanser mungkin menghadapi kesukaran untuk menangungkan rawatan kanser yang mahal. Oleh sebab itu, wawancara tatap muka dilakukan di Unit Radioterapi, Onkologi dan Rawatan Paliatif di Hospital Umum Sarawak untuk mengkaji penderitaan dan bebanan pesakit kanser. Hasil kajian ini menunjukkan bahawa kos rawatan kanser yang dihitung dari segi sosioekonomi yang berbeza dan profil pesakit. Di samping itu, para pesakit kanser menanggung bebanan dari aspek kos kewangan dan kesanan kepada producktiviti dari segi ketidakhadiran dan kehilangan kerja. Anggaran kos penjagaan kanser juga dapat digunakan untuk membuat ramalan dan mengesan perbezaan antara kumpulan umur, tahap pendidikan, tahap kanser dan perjalanan untuk rawatan. Pembuat dasar dan penyediaan untuk strategi penjagaan untuk mengatasi masalah tersebut yang disebabkan peningkatan jumlah pesakit kanser adalah sangat penting. Pengutamaan kanser sebagai masalah kesihatan utama tentunya akan meningkatkan kadar kelangsungan hidup dan mengurangkan beban kewangan.

Kata kunci: Kos kewangan, ketoksikan kewangan, productivity kerja

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# CHAPTER ONE INTRODUCTION

### **1.0 Introduction**

Cancer is the most prevalent illness in Malaysia with a mortality rate of 12.6% at all government hospitals. One in four Malaysians will be diagnosed with cancer by the age of 75 years (Lee, 2018). Receiving a cancer diagnosis often comes as a shock. A shock in health can cause impoverishment brought on by unpredictable spending on health expenditure, reduced functional capacity, increased absenteeism rate and lost income or productivity (World Health Organization [WHO], 1999; Xu et al., 2003). The cancer patient with poor health may suffer from productivity loss in terms of working hours lost, limitations in housework or school, lost income and time spent in bed (Guy et al., 2014). Extra time spent seeking treatment also imposes time costs and financial burdens on them. This may lead to a lower rate of savings, return on capital, level of domestic and foreign investment, contributing to a reduction in economic growth (Ruger et al., 2006).

Apart from this, in ASEAN countries, there is evidence of an additional 30.0% or more spending of household income on out-of-pocket expenses for cancer treatment especially in patients from the low-income group (Kimman et al. 2012a). These patients are more likely to suffer from both financial catastrophe and death. This is because they face a higher financial burden due to massive out-of-pocket spending. Some cancer patients even decide to forgo or delay treatment received. Although the basic treatments such as surgery, chemotherapy and radiotherapy were subsidized by the government, innovative drugs or high-tech treatments with better prognoses required extra spending from the patients. Technological advancement has led to

higher treatment costs that might impose extra financial burdens. This minimizes accessibility to better and more effective treatment and lowers the quality of life on cancer patients.

In this case, financial affordability, a component to ease the accessibility of treatment for the patients becomes important. The higher the treatment accessibility, the higher the possibility of surviving and getting cured. The improvement in survival rate; however, does not account for progress against cancer due to behavioural or biological differences or choices made on treatment (American Cancer Society, 2019). For example, the cancer survivor might suffer from a recurrence where it may occur days, months, or even years after the diagnosis of the primary or initial cancer. The doctor cannot say for certain whether the cancer will recur as the probability of survival depends on the type of primary cancer. This often comes along with additional treatment costs during short or long-term follow-up. Thus, the ability of cancer survivors to continue employment and be accepted in the workplace becomes an important criterion in their decision whether or not to receive further treatment. Overall, health has a direct effect the economic growth through labour productivity and the economic burden of illnesses (WHO, 2009).

### **1.1 Definition of Cancer**

Cancer is a disease caused by changes in cells leading to abnormal growth. It is found when body mechanisms stops functioning normally triggering an uncontrolled development of abnormal cells in the body. In general, abnormal cells are the old and damaged cells that fail to be replaced by new cells and grow to form a mass of tissues known as tumours. Tumours can be categorized into malignant and benign tumours. A malignant tumour (cancer) can endanger lives as it can metastasize through the blood or lymph system or infiltrate and destroy adjacent cells whereas a benign tumour cannot. Cells experience unusual changes known as hyperplasia and dysplasia prior to the formation of cancer cells in tissues, but they may or may not be cancer that can be controlled and treated. The only major cause of death from cancer is metastasis but early treatment can prolong the lives of patients (WHO, 2019; NCI, 2015).

Cancer can be inherited or caused by certain environmental factors such as cigarette smoking, chemical products and radiation such as sun rays. Each patient has different unique genetic changes that trigger the formation of different cancer cells. Additional changes will occur when cancer continues to develop. Changes in genes like proto-oncogenes, tumour suppressor genes and repair genes cause formation of cancer cells (NCI, 2015). It happens when the proto-oncogenes become more active, causing growth and division of normal cells in an uncontrolled manner. At the same time, tumour suppressor genes and DNA repair genes fail in fixing damaged DNA.

Cancer can be classified into stages with TNM system where TNM stands for tumour, node (lymph node) and metastasis (Canadian Cancer Society, 2018). There are five stages from 0 to 4 (commonly given as Roman numerals I, II, III and IV). Stage 0 is known as carcinoma in situ, Stage I is when the tumour is small and confined within the organ, Stages II and III are when the tumour is growing outside the organ and infiltrating nearby tissues and Stage IV is when the cancer has metastasized through the blood or lymphatic systems. The general types of cancer are carcinoma, sarcoma, melanoma, lymphoma and leukaemia (NCI, 2015). Carcinomas commonly occur in skin, lungs, breast, pancreas and other organs and glands. Lymphomas are cancers of lymphocytes and leukaemia is cancer of the blood. Sarcomas develop in bone, muscle, fat, blood vessels, cartilage and other soft or connective tissues whereas melanomas are found in the pigment skin cells. Cancer is a human ailment that has been recognized since a thousand years ago. Researchers have worked for years to find ways to combat cancer. Today, cancer can be treated with modern technology that sustains a longer survival rate.

#### **1.2** Symptoms of Common Cancers

## 1.2.1 Symptoms of Breast Cancer

In general, early breast cancer has no symptoms and is frequently diagnosed through mammography screening. The common symptoms for breast cancer are a lump or mass in the breast. Other symptoms may include persistent changes to the breast such as thickening, swelling, distortion, tenderness, skin irritation, redness, scariness, and nipple abnormalities or spontaneous nipple discharge (American Cancer Society, 2019). Evidence shows clinical breast examination and mammography minimizes the rate of mortality due to early detection and treatment (Yucel et al, 2005). However, scarce resources in Malaysia for mammography has lead to an encouragement for breast self-examination (Hisham & Yip, 2004; Hadi et al., 2010). However, like other screening tools, mammography can misinterpret the presence of breast cancer where 10 out of 100 women were screened had an abnormal mammogram but only 5 out of 100 women had cancer (American Cancer Society, 2019).

Among the mammograms, full field digital mammography (FFDM) is highly recommended and at the same time needed to improve the detection of microcalcifications. Moreover, a new diagnostic tool known as magnetic resonance imaging (MRI) is suggested to be used with mammography in the United States but less likely to be used for routine screening in Malaysia (Yip, Pathy & Teo, 2014; American Cancer Society, 2019). Treatment for breast cancer highlights surgery and adjunctive therapy (chemotherapy, radiotherapy and hormone therapy); however, there is a concern for treatment such as hypercalcemia, neutropenia and preservation of fertility.

## 1.2.2 Symptoms of Colorectum Cancer

The symptoms include rectal bleeding, bleeding from the anus, changes in bowel habits or stool shape, feeling the colon is not completely empty, abdominal pain or cramping, reduced appetite, and loss of weight. In some circumstances, the cancer can also cause blood loss that leads to anaemia that causes the presence of weakness and fatigue. Risk factors for colorectal cancer include obesity, body deficiency, smoking, high consumption of red or processed meat, tobacco, poor calcium intakes, fruit and vegetables and a family history or traits. Aspirin is one of the drugs used to reduce risk. However, serious adverse health effects such as gastrointestinal bleeding are associated with aspirin use.

In the early stages, colorectal cancer patients are asymptomatic. Thus, early screening is encouraged. In Malaysia, colorectal cancer is managed with surgery, adjuvant or palliative chemotherapy and radiotherapy (Ghee, 2014). Neoadjuvant chemoradiation is an adjuvant chemotherapy that is used to treat the cancer. Nevertheless, a high percentage of anastomosis leakage has been detected in patients with diabetes, low albumin levels, higher staging, poorly differentiated tumours and patients that underwent neoadjuvant radiotherapy (Teoh et al., 2005). A newer treatment option is immunotherapy.

#### 1.2.3 Symptoms of Lung Cancer

The signs of lung cancer include persistent cough, blood in sputum, chest pain, speech alterations, worsening breathing problems and recurring pneumonia or bronchitis. In fact, until the illness is advanced, there are often no signs. Exposure to radon gas and second-hand smoke, asbestos, metals (chromium, cadmium, arsenic), organic chemicals, toxins, air pollution, and diesel exhaust are some of the risk factors for cancer (cigarette, cigar and pipes). Common occupations with increased risk of lung cancer include people working in rubber production, chimney cleaners, painters, pavement pavers and roofing installers.

In Malaysia, most cases of lung cancer were either diagnosed when locally advanced or with distant metastasis at the late stage. There was a significant delay for treatment due to failure of detection and beliefs in traditional complementary medicine (Loh et al., 2006). Surgery is the main option for treatment and continued with chemotherapy and radiotherapy. The chemotherapeutic drugs kill cancer cells such as apoptosis and reduce the incidence of metastasis after the 5<sup>th</sup> and 6<sup>th</sup> cycles of treatments; nonetheless, the sample size of the study was small and further study was required with a larger sample size (Siang & John, 2016).

## **1.2.4 Symptoms of Nasopharyngeal Cancer**

A lesion in the throat or mouth that bleeds easily and does not heal, ear pain, a neck mass and coughing up blood are symptoms of cancer patients in the early stage, as well as a continuing red or white patch, lump or thickening in the throat or mouth. Common late symptoms such as difficulty chewing, swallowing and moving the tongue or jaw. The risk factors are use of tobacco and excessive consumption of alcohol. HPV infection of the mouth and throat which is transmitted through sexual contact also increases the risk.

Radiotherapy, histopathological examination and imaging modalities such as chest X-ray and abdomen ultrasound are commonly used in Malaysia (Abdullah, Alias & Hassan, 2009). Computerised tomography (CT) which is a modern spiral CT scan is less likely to use for detection in Malaysia. Besides this, nasopharyngeal swabs that has high sensitivity and specificity in detecting NPC is used in Taiwan whereas nasopharyngeal brush biopsy is commonly used to detect the presence of Epstein-Barr virus (EBV) in South China, Taiwan and Hong Kong. (Prasad et al, 1989; Hao, Tsang & Chang, 2003).

## **1.3** Overview of Cancers Trends

Cancer in general is the leading cause of death globally, with 8.2 million deaths reported in 2012 alone based on a report released by the International Cancer Research Agency (IARC), the world's cancer agency. Meanwhile, in the coming two decades, 70 percent of global cancer deaths are projected to be from low to middle-income countries–a category that most Southeast Asian countries fall within. Cancer not only has a direct effect on patients with cancer, but also affects people in their neighbourhood, including relatives, family members and colleagues. The high cost of cancer treatments from radiation treatment to chemotherapy has put enormous pressure financially and emotionally on cancer patients and their family members.

Figure 1 provides a mixture of and independently for men and women the distribution of prevalence, mortality and total cancer by global region. It is predicted in both sexes that almost half of cancer cases and more than one fourth of the deaths worldwide in Asia will occur in 2018, partly due to the fact that almost 60.0% of the world population lives there. Europe accounts for 23.4% of all cancer cases and 20.3% of cancer deaths, though it accounts for only 9.0% of the world population, followed globally by America's 21.0% prevalence and 14.4% mortality. In comparison to the other countries, the number of cancer deaths in Asia (57.3%) and Africa (7.3%), because of the different spread of cancer types and the higher rate of mortality, is greater than those in the other regions (48.4% and 5.8%, respectively).



Figure 1.1: Global Estimated Number of Cancer Incidences and Mortality, 2017

Source: The Global Cancer Observatory (2018).

Cancer is projected to grow to 21.7 million new cases by 2030, from 14.1 million in 2012. The disease is of utmost global concern with 9.6 million cancer deaths worldwide in 2018 alone. Research shows that this epidemic will burden low and middle revenue (LMICs) countries the most. Eight out of ten ASEAN countries: Cambodia, Indonesia, Laos, Malaysia, Myanmar, the Philippines, Thailand and Vietnam are LMIC countries. The huge increase in cancer cases in these countries is due to an aging population, which is at greater risk of cancer, the use of cigarettes, food reform and lack of physical activity, air contamination which contributes to some cancers including lung cancer, and higher numbers of patients with infectious diseases which contribute to certain carcinomas, such as cervical cancer and liver cancer. The result is an increase in the number of cancers. The threat of cancer is urgently in need of mitigation. Non-communicable Diseases (NCD) also have a large social impact in ASEAN, apart from the potential overload of these countries' healthcare costs and systems. In the ACTION report, over 75 percent of patients die or face financial disaster within one year of their diagnosis (Kimman et al., 2012a). One third of the surveyed families suffered economic difficulties and were unable to pay for medication, mortgages and utilities.



Figure 1.2: Estimated Number of Incidences, Mortality and Prevalence in 2018, South-Eastern Asia, All Cancers

Source: The Global Cancer Observatory (2018).

Figure 1.2 showed Malaysia is ranked at the sixth among the 10 countries in 2018. It is forecasted that 4.4%, 4.2% and 5.2% of incidences, mortality and prevalence rate in Malaysia accordingly. Furthermore, both Indonesia and Thailand accounts for 35.3% and 17.2% of new cases, followed by Vietnam (16.6%), Philippines (14.3%), Myanmar (7.0%), Singapore (2.6%) and others (2.5%). Among all these countries, a massive total estimate of 631,190 death cases which accounted for 11.5% of mortality rate in Asia. In Malaysia, cancer happened in people at 30 years old or older and the incidence rate in males exceeded the incidence rate in female after the age of 60 years. Approximately 86.9 of 100,000 men and 99.3 of 100,000 women are diagnosed with cancer. The likelihoods are assessed based on the total cancer population and could be undervalued or overestimated due to variations in overall exposure, such as tobacco, alcohol use, environmental damage, parental history, or other factors (WHO, 2019; American Cancer Society, 2019).

On the other hand, the majority of cancer patients studied in National Cancer Registry, National Cancer Institute & Ministry of Health Malaysia (2018) were Chinese (43.2%), followed by Malays (40.7%), Bumiputera (8.6%), Indians (6.6%) and other ethnic groups (0.8%). Figure 1.3 shows the top four cancers in Malaysia are breast, colorectal, lung and nasopharyngeal cancer. From 2007 to 2016, an upward trend from 11.3% to 12.6% of cancer mortality rates identified in Malaysia and resulted in proportion of medically certified and non-medically certified of cancer mortality rates at 64.3% and 35.7% respectively (Azizah et al., 2016; Azizah et al., 2019). Additionally, the cancer incidence in males and females were 86.9 and 99.3 per 100,000 population respectively and an estimation of 55000 new cancer cases are

forecast for the year 2030 in Malaysia (Azizah et al., 2016; Azzani et al., 2017). Both the incidence and mortality rates of the top 5 common cancers in Malaysia are breast (47.5 vs 18.4), colon (19.9 vs 11.2), lung cancers (15.3 vs 13.3), nasopharyngeal (6.3 vs 3.7) and liver (6.3 vs 6.3).

More specifically from year 2007 to 2016, breast and colorectal cancers' incidence rate were increasing which showed that an improvement on actions taken was needed to be taken to combat the diseases whereas lung and nasopharyngeal cancers were declining and reflected the effectiveness of cancer control and strategies by the government (Azizah et al., 2016; Azizah et al., 2019). The growing trend of increasing death rates and incidence levels calls for early detection to be strengthened by screening and signs recognition and care of higher rates of care during Phase I. However, from 2007 through 2016, Malaysians rose the overall 5-year survival rate of Malaysians rose to 58 percent for all cancers. The highest recovery rates among women and younger age group were in thyroid cancers (82.3%), prostate cancers (73.0%), uterine corpus (70.6%), female womb (66.8%) and female conception (56.8%). Cancers such as lung, tracheal and bronchial cancer have the lowest survival rate at 11.0%. A higher rate of cancer survival showed more cancer patients living longer after diagnosis that contributed to the increased of the prevalence. Thus, there is a massive requirement to focus on several areas such as long-term cancer treatment effects and issues as well as medical follow-up by increasing research on the needs of cancer survivors (Hayat et al, 2007).



Figure 1.3: Estimated Number of Incidences, Mortality and Prevalences in 2018, Malaysia, Top 10 Cancers

Source: The Global Cancer Observatory (2018).

The top five most frequent cancers in Sarawak among males are nasopharyngeal, lung, colorectal, stomach and NHL whereas females suffered from breast, cervix uteri, lung, ovary and colorectal cancers (Azizah et al., 2016). Like the rest of Malaysia, Sarawak shared the same top four cancer types which were breast, lung, colorectal and nasopharyngeal cancers. The rise in incidence rate of cancer cases in Sarawak is shown in Table 1.1. In both Malaysia and Sarawak, breast cancer was the leading cause of cancer that put the cancer patients at risk from 2007 to 2018 (refer to Figure 1.3 and Table 1.1).

No	Type of Cancer	2014	2015	2016	2017	2018	Total
1	Breast	308	365	368	356	370	1,767
2	Colorectal	204	255	252	277	303	1,291
3	Lung	193	189	221	239	247	1,089
4	Nasopharyngeal	201	187	177	194	188	947
Total		906	996	1,018	1,066	1,108	5,094

 Table 1.1: Top Four Cancer Types in Sarawak, 2014-2018

Source: Sarawak General Hospital (2019).

From year 2014 to 2018, breast cancer cases increased from 308 to 370 in Sarawak. Both colorectal and lung cancer increase gradually at 48.5% and 28.0% respectively. A decreasing number of nasopharyngeal cancer cases from 201 cases in year 2014 to 188 cases in year 2018. The growing trend of cancer cases for breast, colorectal and lung cancer could indicate a lack of proper prevention or awareness among the people in Sarawak. Hence, further action is needed to tackle these cancers especially lung cancer which has a low survival rates at 11.0% only whereas the remaining cancers have survival rates over 50.0% (National Cancer Registry, National Cancer Institute & Ministry of Health Malaysia, 2018).

### **1.4 Economic Burden of Cancer Care**

Research addressing the economic burden using terminologies such as financial hardship, financial toxicity, financial burden, financial distress, financial stress and economic hardship that reflect similar general concepts in general (Parsons et al., 2018; National Cancer Institute, 2019). Davidoff et al. (2015) defined financial hardship as delayed or unmet need for medical, prescription, or dental care because of cost or insurance issues and/or family out-of-pocket medical spending that was 20.0% or more of gross income. A massive proportion of direct out-of-pocket spending on health and cancer will drive up household consumption of health-related goods and services at the expense of non-health goods and services (WHO, 2009). The consumption of non-health is defined as the consumption on goods and services that do not relate to disease or injury such as social cost, leisure and health status from the perspectives of households. Nevertheless, a reduction in the production of both market and non-market goods such as consumption and working hours occurred by spending extra time on seeking care. This impact is not limited to a certain time period, spending on health goods and services can occur from current income or future assets.

The major contributions to growth on cost of health care comprises of demographics (ageing population), innovation (technology), lifestyle (abuse), structure (incentives), relative price effects (skill intensity), standard of living (quality of life expectations) and information (educated consumer) (Office of Health Economics, 2019). Health expenditure is the health care costs for treatment and diagnosis in monetary value and is a tool to combat the illness and attain better state of health. Additionally, it also reduces other illness-related costs as a better state of

health or a faster recovery lead to fewer productivity losses, less informal care and a reduction of pain and suffering (WHO, 2009). However, cost of utility and benefit, the costs based on economic theory, also commonly known as the costs of society welfare.





*Sources*: WHO Global Health Expenditure Database (2018); OECD Health Statistics (2018).

Figure 1.4 indicates health care investment rates in Asia-Pacific countries and regions in 2015 carried out by OECD/ WHO (2018). Health expenditure ranges from Bangladesh's per capita health expenditure of only USD 88 (USD PPP) to Australia's

USD 4 491 (USD PPP). Average OECD health expenditure per person in 2015 was approximately 20 times that of the Asia Pacific (3,800 compared to USD PPP 193) for the low-income countries and territories. The higher the level of income in a country, the greater the per capita proportion of government or compulsory spending on health in Asia Pacific. This is shown by the 71.6% in countries with high incomes compared to 36.8% in low-and medium-income countries spending on health expenditure. In low and middle-income, Asia Pacific countries' health expenditure accounted for 4.3 percent and 7.3 percent of GDP respectively in 2015. There were increases in 0.4 and 0.8 percentage points were increased as compared to 2010. As a share of GDP, Japan was the largest investor in 2015 with an over 1 percent of its GDP spending on health and social construction, equipment and technology. Capital expenditure will, however, can be significantly less. The average figure for non-OECD countries Asia Pacific was 0.3 percent of GDP and is below 0.2 percent in 2015 in Bangladesh, Brunei Darussalam, Malaysia, Cambodia and the Philippines.

### 1.5 Impact of Cancer Care On Social Economic Development

The cost-of-illness (CoI) framework gives an overview of the macroeconomic impact of health, for example spending on the health care sector and reduction of labour productivity where the contribution of diminished accumulation of capital, human capital assets and demographic changes to declining economic growth could not be taken in (WHO, 2009). Most studies used the CoI approach to predict the impact of certain diseases at a national level. With this approach, the feasible economic consequences of specific illnesses are divided into 'direct cost', 'indirect cost' and 'productivity loss'. The direct cost – the spending incurred due to illness (including medical care, travel cost, household assistance and conversions or aids) and indirect cost – the value of lost production due to lost productivity, employment disability, missed workdays, lost household productivity and lost leisure time. When calculating productivity loss, human capital approach is often used to calculate the potential of an individual on production based on average wage. Other methods such as the friction cost approach is also used to calculate productivity loss based on the salary used for new hire on replacement. Besides direct and indirect costs, a full capture of the health expenditure must also include intangible costs – suffering and pains.

Besides the valuation of cost-of-illness (CoI), willingness-to-pay (WTP) also determines the cost of illness and welfare. WTP provides a more comprehensive view on overall economic welfare losses resulting from disease and injury; however, there are problems with practical implementation and thus recommended to be empiricallybased (estimation on market losses) and hypothetically-based (estimation on forgone welfare). Moreover, measurement on morbidity and mortality are key considerations for predicting the burden of cancer in populations and followed by life expectancy, quality of life, quality-adjusted life expectancy, disability life expectancy, healthydays equivalent and activities of daily living are all measures of disease burden related to health outcome (WHO, 2009; Centres for Disease Control and Prevention, 2019). In addition, the consumption of non-market activities such as housework or leisure time to take care of the sick household member will also decline.

Under this circumstances, the ability to work and recover from sickness in order to get back to the workplace and earn money for extra spending on health goods and services becomes crucial. This effect on health costs in combination with healthcare and technological advances is particularly important. Innovations in the healthcare industry are creating new technology, medications and treatments that are typically cheaper than the current ones, but which allow diseases to be handled in return more quickly and effectively. For example, minimally invasive treatments like laparoscopy have now allowed hernia patients to go back to work with considerably fewer pain and almost twice as quickly following surgery. However, the improvement in technological treatment increases the treatment cost and imposes an extra burden on them.

A reduction on household income, savings and assets due to consumption of health goods and services may eventually lead to depleted investment such as on physical capital, financial capital and human capital and imposes an unpredictable impact on consumption in the coming years. The cancer burden will only continue to grow globally, exerting tremendous physical, emotional and financial strain on individuals, families, communities and health systems (WHO, 2019). Most health systems are less able to deal with this problem in low and middle-income economies and many cancer patients world-wide are not offered prompt clinical care and therapy. The effect is preventable cancer pain and death. Nevertheless, the survival rate of many types of cancers in countries that have good health systems increases and is attributable to effective early detection and high-quality screening and recovery care.

## 1.6 Issues and Challenge in Cancer Care

Based on the ACTION study conducted by Kimman et al. (2012a, 2012b), only 23.0% of cancer survivors are not burdened financially. There were 29.0% of cancer patients dead and approximately 48.0% of them suffered from financial catastrophe. This study concluded that there was an additional 30.0% spending or more of household income on out-of-pocket expenses for cancer treatment and the patients from the low-income group were more likely to suffer from both financial catastrophe and death. Besides this, those with an initial diagnosis of late-stage cancer had a five times higher mortality rate compared to those with early-stage cancer. Among these patients, approximately three-fifths of the patients undergo financial stress which is similar to the overall rate of financial hardship of 45.0% in Malaysia.

Furthermore, 90.0% of the cancer patients in the study were from public hospitals which offer with heavily subsidised treatment. The result stating that cancer patients were highly affected by the treatment cost is supported by Universiti Malaya cancer epidemiologist and principal investigator for Action in Malaysia Associate Professor Dr Nirmala Bhoo-Pathy. There was an extra spending on chemo ports, innovative therapies such as immunotherapy, basic biomarker tests and palliative care. Although free treatment on basic chemotherapy provided for free by the government; nevertheless, innovative drugs or high-tech treatments that provided better treatment outcomes require extra spending from the patients. Therefore, it was undeniable these extra spending will push some people to poverty and lower the accessibility to the treatment especially for patients from the low-income group. At the same time, there is inequality in treatments received by the cancer patients from the high-income group, medium-income group and low-income group due to the difference level of financial affordability. The following table further explains the challenges of cancer control in Malaysia:

Cancer Continuum Focus	Challenges		
Etiology and Prevention	Five million people currently smoke in Malaysia where		
	tobacco is an essential (16 types) risk factor for cancer.		
	In south-east Asia, Malaysia has the largest obesity rate		
	- unhealthy diets and physical inactivity are linked to		
	many types of cancers.		
Detection	Cancers are typically identified or treated in Malaysia		
	late (Stage III or IV) - late diagnosis has a drastic		
	impact on survival rates. For example, patients with		
	stage I diagnoses have an 88.0% likelihood of five years		
	of survival relative to those diagnosed at stage IV who		
	have a 23.0% chance of survival.		
Diagnosis	Key providers of health care may not have sufficient		
	cancer information, which might lead to incorrect		
	clinical tests and clinical diagnosis delays. With weak		
	health literacy, patients may not partake in shared and		
	informed decision making.		
Treatment and	Oncologists are scarce in Malaysia with only 115		
Survivorship	oncologists in 2019. Malaysia has 3.4 oncologists for		
	every one million people at a time, when the ideal ratio		
	for the same number is 8-10 oncologists. In the		
	ASEAN region, one year after diagnosis the Malaysians		
	endure the greatest risk of economic hardship.		

Table 1.2: Ch	allenges c	of Cancer	Control in	Malaysia
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Source: National Cancer Society Malaysia (2018).

With the growing burden of cancer, seen by the growing number of cancer patients, Malaysia's multi-sectoral effort to control cancer is increasingly urgently needed. This calls for the involvements of various players such as policymakers, health planners and administrators from regional and facilities, academic societies, clinicians, as well as civil societies as a whole to be included (Murallitharan et al., 2018).

## 1.7 Problem Statement

Cancer is a major global health concern. The out-of-pocket expenditure of cancer treatment will lead to inequality of financial toxicity. Generally, financial toxicity can be measured from both 'objective financial burden' and 'subjective financial distress' by cancer patients (Carrera, Kantarjian & Blinder, 2018). Studies on the individual financial impact of cancer therapy to date has focused primarily on quantifying subjective financial burden such as out-of-pocket (OOP) spending (Bestvina et al., 2014). Whereas, the objective financial burden of cancer treatment of cancer treatment of cancer from a provider perspective in Universiti of Malaya Medical Centre. To date, past studies mainly focus on neither objective nor subjective of financial burdens. As a result, there is an absence of a complete practical way to measure the economic cost; in fact, it is difficult to fully capture the true cost of cancer treatments. Therefore, this study aimed to determine both the objective and subjective financial burden of cancer in broader sense, covering the top four cancer disease which constitute more than 40 percent of cancer incidence in Sarawak.

Moreover, side effects of cancer treatment could cause a deterioration in health and potentially reduce the work productivity as well as income. It is known that cancer has an impact on ability to work (Lerner et al., 1999; Malaguarnera et al.,2013; Cleeland et al., 2014). However, little of research quantify the productivity loss due to cancer. As the treatment or therapy is potentially affected by job performance and resulting in income losses, early retirement or disability to work. This might lead to underestimate the full economic burden of cancer. Therefore, this study will be taking
into consideration of capturing the burden of cancer illness in both direct cost (medical and non-medical cost of cancer care) and indirect cost (productivity loss and time off on each visit) due to cancer.

Furthermore, the cost-of-illness (COI) approach is a common approach in measuring burdens associated with certain diseases in both prevalence and incidence at national level. The estimation of socioeconomic costs of a disease throughout the lifespan, from its initial stage to the patients' complete recovery or death. In reality, it is difficult to estimate the national cost-of-illness due to the sheer volume and complexity of data. On the other hand, cost of illness estimation only considers healthcare resources spent and productivity loss incurred. In fact, it did not reflect the socio-economic variables including (household income, treatment hospital) as well as clinical profile (cancer stages, type of treatment) of population. Hence, this study aimed to address the burden of disease from a household perspective to gain an in depth understanding of the association between burden of illness and socio-demographic variables as well as clinical variables.

In this sense, a more comprehensive study on the economic burden of cancer cases shall be addressed by computing the expenditure due to cancer care, productivity loss extended from cancer treatment as well as the subjective measure of financial toxicity due to the cancer care. Hence, the research questions include:

- 1. How big is the costs of cancer care for top four cancer types in Sarawak?
- 2. How much is the work productivity loss due to cancer?
- 3. What is the level of financial toxicity among the cancer survivors?

4. What are the predictors of financial toxicity among the cancer survivors?

#### **1.8 Research Objectives**

## **1.8.1 General Objective**

The objective of this study is to estimate the burden of illness of cancer, focusing on the economic perspective of disease burden among cancer survivors in Sarawak.

## 1.8.2 Specific Objectives

- 1. To compute the costs of cancer care for the top four cancer types in Sarawak;
- 2. To quantify the work productivity loss of cancer survivors;
- 3. To estimate the level of financial toxicity among the cancer survivors; and
- 4. To identify the predictors of financial toxicity among the cancer survivors.

## **1.9** Significance of the Study

Financial toxicity captures both objective and subjective financial burden in this study. Thus, information from this study can provide a baseline comparison for national planning of health budgets such as strategies planning, priority setting and forecasting for future cost for certain health programmes. Moreover, a more sensitive capture of financial burdens imposed on cancer patients will enable policy makers to adjust or develop better indicators that help to lower the financial distress.

Besides this, it is believed that an estimation of the economic burden of cancer is believed even more crucial to convince the health administrators of specific disease to encourage a greater engagement in prevention or early detection of a specific disease. Hence, this study provides information for the government to allocate the resources wisely to cope with the demands of society. Other financial institutions can also cooperate with the government to fulfil the demands of the cost of sudden illness imposed on cancer patients. For example, the collaboration between government and third-party health system to negotiate for low prices for specific cancer treatments from drugs provider companies.

The study also useful to the insurance agencies. It allows insurance agencies to specifically look at the effects of insurance coverage on patients. Insurance coverage might be underused or overused due to different preferences and consumption behaviours. With a more accurate idea of the financial burden on cancer patients, insurance companies are able to adjust the ceiling for co-payment rates and remove unnecessary coverage items in order to narrow the gap in health service utilization among cancer patients. Uninsured patients may face higher prices than insured patients. This study therefore provides information about charges and protection from insurance companies to patients

The public can gain benefits from this study as well. Lost earnings caused by cancer make budget constraints more serious. The heavy financial burden in some households will affects its capability to pay for health care and essential needs. This study gives early signals to the public on the benefit of early detection or prevention on specific cancers. At the same time, knowledge on specific cancers studied in this research offers awareness among the public and urges for better treatment decisions at the beginning of cancer diagnosis.

## 1.10 Organization of the Study

This study is structured and presented as mentioned below. Chapter one introduces the topic and provides the background, problem statement and significance of the study. Secondly, chapter two reviews the empirical findings. In chapter three, the methodology used in this study is described in a few subtopics according to the theoretical framework, conceptual framework, hypothesis development, data description, empirical testing and empirical evidence.

## 1.11 Concluding Remarks

Asia has one of the lowest overall cancer rates worldwide, but patients with cancer are more likely to die in Asia. Approximately more than 75.0% of cancer patients have died from or ended up in the financial disaster within one year of diagnosis in Southeast Asia according to the ASEAN oncology (ACTION) report. It has also been shown that in the socioeconomically disadvantaged groups, especially in lowand middle-income countries in which there is a lack of social security networks, economic impacts are the most significant. As the death rate and cancer incidence in both South-East Asia have risen, the economic consequences of the disease for patients and their families is a concern. The lack of resources for health care and cancer specialists pose a challenge. Prioritizing cancer as a major health concern would certainly improve the survival rate and reduce the financial burden of the illness.

## **CHAPTER TWO**

## LITERATURE REVIEW

## 2.0 Introduction

The purpose of this study is to determine the burden of illness on cancer patients from an economic perspective. Previously, many scholars have carried out studies related to this topic. However, the use of different methodologies in this study has its own pro and cons. This chapter comprises  $\Theta f$  a review on varieties of cancer, its financial cost, its economic burden, its impact on QOL and its psychological effects. Studies on both primary and secondary data findings are presented.

## 2.1 Review of Past Studies on Financial Burden of Cancer Care

# 2.1.1 Review of Past Studies on Financial Costs of Cancer Care based on Primary Research

Ekwueme et al. (2014) studied the medical costs and productivity losses of cancer survivors in United States from the year 2008 until 2011. The findings revealed an average \$4,187 higher expenditure for men and \$3,293 higher expenditure for women than for respondents without a history of cancer. Moreover, the annual productivity loss for cancer survivors is greater than for individuals without a history of cancer (men \$3,719 versus \$2,260; women \$4,033 versus \$2,703). Nearly a third of patients experience interference in their daily routines other than work, sustaining long-term and late consequences of treatment. Approximately 10.0% of the survivors under the age of 65 were not insured and likely had a greater personal financial burden and might have experienced financial barriers.

Ezat et al. (2013) provided evidence from a cross-sectional study to determine the cost of colorectal cancer (CRC) management and compared the cost effectiveness in managing CRC between cetuximab and bevacizumab in Malaysia. The results revealed the costs at Stage I RM13,623(12,467-RM14,777) Stage II RM19,753 (RM16,734-RM23,520), Stage III RM24,972, and Stage IV RM27,163 (RM23,192-RM31,133). The incremental costs of Cetuximab and bevacizumab were RM20,556,480, and RM7,557,953 respectively, based on the estimated 2,671 new CRC cases. In contrast, the rates for conventional chemotherapy was less by 50 percent at stage III and stage IV. The incremental costs of cetuximab and bevacizumab per quality adjusted lifetime was RM38,869 and RM14,290. Thus, bevacizumab was considered more cost-effective than cetuximab. The costeffectiveness was sensitive to the percentage of the late stages of CRC. Besides that, both types of monoclonal antibodies were considered cost effective based on WHO's criteria with 3 times lesser of GDP.

Bernard et al. (2011) carried out a panel study on the national estimates of outof-pocket health care expenditure burdens among nonelderly adults with cancer from 2001 to 2008 in the United States. The findings indicated that cancer survivors had a total of S3881 (2008 dollars) on annual out-of-pocket spending. There was high health care burdens in 13.4% of cancer survivors, compared to 9.7% in patients with chronic conditions and 4.4% in patients without chronic conditions, whereby high health care burden was defined as spending more than 20% of income on healthcare. Davidoff et al. (2013) carried out a retrospective and observational study on the out-of-pocket health care expenditure burden for Medicare beneficiaries with cancer from 1997 to 2007. The data was sourced from Medicare Current Beneficiary Survey (MCBS). The findings indicated that the beneficiaries with cancer paid \$4,727 (cumulative 2 years expenditure, 2007 dollars) in out-of-pocket whereas the comparison group paid \$3,209. In addition, the massive out-of-pocket expenditure imposed burdens on 28.0% of the cancer survivors compared to 16.0% of beneficiaries without cancer history.

Guy et al. (2014) found panel study on estimated health and economic burden of cancer among adolescents and young adults' patients from year 2008 to 2011 in United States. The measurement for health burden was determined by direct cost (out of pocket, private health insurance, Medicare, Medicaid and other sources; ambulatory care, inpatient care, prescription medications and other services) and indirect morbidity cost (employment disability, missed workdays and additional days spent in bed). The findings indicated the yearly adjusted out-of-pocket spending for the adult survivors of cancer diagnosed at the age of 15-39 years was \$765 (2011 US dollars) compared to \$686 in adult patients without a history of cancer.

Guy et al. (2015) demonstrated a panel study on the healthcare expenditure burden among non-elderly cancer survivors from year 2008 to 2012 in United States. The data source was from 2008 to 2010 Medical Expenditure Panel Survey. The outof-pocket burden yearly included out-of-pocket expenditures toward any healthcare service such as coinsurance, copayments, and deductibles. The findings indicated that the cancer survivors were more likely to report a massive out-of-pocket burden at 4.3% compared to the cancer patients without a cancer history at 3.4%.

# 2.1.2 Review of Past Studies on Financial Costs of Cancer Care based on Secondary Research

Jacobson et al. (2012) provided evidence on the retrospective and observational study on the cost burden of oral, oral pharyngeal and salivary gland cancers from commercial insurance, Medicare and Medicaid from year 2004 to 2008 in the United States. The data was sourced from National MarketScan CCAE databases. The findings indicated that the annual out-of-pocket spending for survivors with commercial insurance and Medicare were \$2,133 and \$785 more than for controls group.

Jagsi et al. (2014) conducted a longitudinal cohort study on the long-term financial burden of breast cancer on a diverse cohort of survivors identified through population-based registries from year 2005 to 2007 in metropolitan Los Angeles and Detroit. The data was sourced from Los Angeles, CA and Detroit, MI and SEER. The findings indicated that 65.0% of the breast cancer survivors paid less than \$2,000 on out-of-pocket spending, 18.0% of them paid between \$2,001-<\$5,000 and 17.0% of the cancer survivors paid more than \$5,000.

# 2.2 Review of Past Studies on Indirect Costs or Productivity Loss of Cancer 2.2.1 Review of Past Studies on Indirect Costs or Productivity Loss of Cancer based on Primary Research

Dowling et al. (2013) demonstrated a panel study on the productivity loss and burden of illness in cancer survivors with and without other chronic conditions from year 2008 to 2010 in the United State. The results showed the lower job rates and higher limitations in the workforce, housework or school for cancer survivors aged 18-64 years old with chronic disease. Compared to those with neither cancer nor chronic illness; neither heart disease nor diabetes, or diabetes, specific reports for cancer site reports for any constraints in work, housework and school (8.8% -17.5%). The number of people lacking cognitive function and cognitive constraints ranged from 4.7 to 11.7 percent and 3.4 to 8.5 percent.

# 2.2.2 Review of Past Studies on Indirect Costs or Productivity Loss based on Secondary Research

Yabroff et al. (2005) published a population-based study on estimated time costs of patients associated with the colorectal cancer care from year 1995 to 1998 in the United State. The findings indicated the net patient time costs for the 3 phases of colorectal cancer care averaged \$4,592 (95.0% confidence interval CI \$4,427–\$4,757) and \$2,788 (95.0% CI \$2,614–\$2,963) over the 12 months of the initial and terminal phase respectively and followed by \$25 (95.0% CI:\$23–\$26) per month in the continuing phase of care. There were more than two thirds of these estimates accounted for hospitalization. Besides that, patient time costs such as direct medical costs was at 19.3%, 15.8% and 36.8% in the initial phase, continuing phase and terminal phase of care accordingly.

Drolet et al. (2005) carried out a population-based study related to work absence after breast cancer diagnosis. The findings indicated that work absence constitutes a negative aspect of cancer experience. Cancer free breast cancer survivors had a higher absence rate from work for 4 weeks and above in the first year after diagnosis compared to healthy women. In the subsequent three years, cancer-free breast cancer survivors no longer experienced a higher absence rate from work. However, the women that experienced other new cancer events continued to be absent from work for longer periods of time especially receivers of adjuvant chemotherapy. Moreover, the self-employed or non-union survivors were more likely to report no work absence compared to those that belonged to a union.

Hanly and Sharp (2014) conducted a study on the cost of lost productivity due to premature cancer-related mortality. This study aimed to measure the cancer burden from a public health perspective. The findings indicated that there was a significant relationship between productivity loss and cancer- related premature mortality. There was a higher premature mortality cost for male patients which is a reflection of their higher wages and rates of workforce participation compared to female patients. The productivity costs conducted in this study provided an alternative perspective on the cancer burden that adds value to cancer control policy decision making.

Pearce et al. (2018) carried out a population-based cross-country cost analysis to predict the value of productivity loss in 2012 due to cancer-related premature mortality in the major developing economies or BRICS countries. The overall cost of productivity losses in BRICS countries as a result of premature cancer mortality was \$46.3 billion, which represented 0.33 percent of the combined domestic gross product. China suffered the largest total loss of productivity at \$28 billion, with the highest expense of \$101,000 per cancer death occurring in South Africa. For Brazil, the Russian Federation and South Africa, total productivity losses were highest from lung cancer. In China, the highest productivity losses was highest from liver cancer, and for India, it was from lip and oral cavity cancers.

Dahl et al. (2017) provided evidence for a cohort study on productivity loss due to breast cancer in Norway. The finding indicated that productivity loss due to the diagnosis within the 13 studied years was estimated to  $102,600 \notin$  per case, with 95.0% CI (88,500, 116,700). The life-long estimate was  $119,200 \notin$ , CI (95,400, 155,600). The national productivity loss in yearly was estimated to be  $179,900,000 \notin$  or  $58,200 \notin$  per case. Patients below 65 years old that were still under diagnosis were claimed at an estimated amount of 94,300  $\notin$  per case. On the other hand, the estimated life-long productivity loss highly relied on the age at diagnosis.

Merola et al. (2018) carried out retrospective cohort study to compare the costs associated with productivity loss among patients in the United States who were newly diagnosed with multiple myeloma receiving oral with those receiving injectable chemotherapy from 2008 until 2015. The findings indicated that the different type of treatment was a significance predictor of disability benefit use and costs associated with loss of productivity. Injecting therapy patients skipped an average of 110 working days in one year following diagnosis and had a gross productivity cost of \$18,315. On the other hand, those patients who obtained oral drugs lost a total of \$14,429 in productivity costs and missed an average of 87 working days a year after their diagnosis.

Chang et al. (2004) carried out a retrospective matched-cohort control study on estimation of cancer costs arising from insurance compensation studies diagnosed in seven cancer groups in the United States. The average health care costs for prostate cancer and pancreatic cancer, was \$2,187 and \$7,616 respectively. Health expenses were \$329 a month and cancer employees were affected by indirect morbidity of \$950, with an annual average loss of 2.0 workdays and 5.0 STD days. Relative to controls, survivors of cancer also reported higher monthly absenteeism (\$373 vs \$101) and higher monthly average short-term impairment (\$698 vs \$25) days. On the other hand, the number of days missed by the caregiver monthly was higher (2.2, vs. 1.4) and there was an association with higher spending (\$161 versus \$255).

Jayadevappa et al. (2010) carried out an observational prospective cohort study on the burden of out-of-pocket and indirect costs of prostate cancer from year 2000 to 2005. The data was sourced from Urology clinics of medical centre and the Veterans Administration Medical Center. The study focused on the out-of-pocket expenditure directly or indirectly including time costs, travel time, number of missed workdays and total imputed indirect costs. The findings indicated that the out-of-pocket spending on receiving prostatectomy and radiation at 24 month followed-up was \$330 and \$661 respectively. The average of indirect costs and time costs at 12 months was \$256 and \$341 respectively for prostate cancer patients whereas it was \$380 and \$ 187 respectively for cancer patients who received radiation therapy. Wan et al. (2013) provided evidence on a retrospective matched-cohort study to compare the indirect costs of productivity loss between the metastatic breast cancer (MBC) and early stage breast cancer (EBC) patients and their family members from year 2005 to 2009 in the United State. The reported total annual cost for survivors of breast cancer, survivors of metastatic breast cancer and controls for total per-capita indirect leave was \$2,383, \$1,775, and \$1,282 respectively. However, for EBC, MBC and control, the indirect payments for short-term disabilities was \$ 6,165, \$ 3,690 and \$558 respectively. The costs for caregivers' leave was 1,075 and 808 dollars for both MBC and EBC respectively.

Huntington et al. (2015) demonstrated a cross-sectional pilot study on the financial toxicity in insured patients with multiple myeloma from August 2014 to January 2015 in the USA. The data was sourced from Philadelphia, PA and Academic Medical Center. The findings indicated a mean COST value of 23 for the cancer survivors. The COST ratings were strongly linked to the use of treatment expenditure approaches identified by patients. At least a minor degree of financial hardship was experienced for 90 per cent of cancer survivors with COST score below the 23.38 percent of those surveyed reported stopping working, 12 percent had reduced working hours, 20 percent had no change in their working hours and 2 percent had increased working hours.

### 2.3 Review of Past Studies on Empirical Findings of Economic Burden

# 2.3.1 Review of Past Studies on Economic Burden of Cancer Care based on Primary Research

Guy et al. (2013) carried out a study on the economic burden of cancer survivorship among adults in the United States. This study investigated the approximate effect of medical costs and loss of productivity of cancer survival. The findings showed that cancer patients who are newly diagnosed had an annual excess economic burden. Cancer patients aged 18 to 64 and 65 years and above had an economic burden of 16,213 dollars and 16,441 dollars respectively. The excess burden per year for those aged 18-64 years was \$4,427 and those aged 65 years and above was \$4,519 among newly diagnosed cancer patients. The excessive medical spending imposed among survivors of cancer, especially those recently diagnosed, constituted the largest share of the economic burden.

Davidoff et al. (2015) provided evidence on a panel cohort study on the affordable care act and expanded insurance eligibility among the nonelderly adult cancer survivors from year 2008 to 2011 in United States. The study focused on the financial hardship measurements such as out-of-pocket spending and delayed or unmet need for medical, prescription and dental care. The findings indicated that 18.0% of the cancer survivors reported financial hardship whereas 37.0% of the uninsured cancer survivors complained on financial distress.

Bestvina et al. (2014) demonstrated on a cross-sectional survey study on follow-up assessing medication adherence, patient out-of-pocket costs associated

with cancer care and financial hardship from year November 2012 to June 2013 in North Durham. The results were pilot-tested at Duke Cancer Institute on a group of 20 patients and at three rural oncology clinics. The study was based on self-reported demographic data, cost-effectiveness decisions, objective, subjective financial burden and failure to comply with medicines. The results show that 16.0% of cancer survivors have reported enormous or worried financial difficulties.

# 2.3.2 Review of Past Studies on Economic Burden of Cancer Care based on Secondary Research

Kimman et al. (2012a) provided evidence on the latest cancer rates and cancer burden among the ASEAN region. This finding indicated the highest burden of cancer in terms of DALYs lost was Laos, Vietnam and Myanmar. Followed by the lowest in Brunei, Singapore and Philippines. A total number of 52.0% and 48.0% of female and male cancer patients suffered lost in DALYs where female highly claimed on breast cancer, followed by cervix and lung cancers. Besides, male patients claimed on liver and lung cancers. Besides that, the population age distribution on cancer rate and mortality was the key findings that showed a huge impact on this study. The rising cancer rates in ASEAN were presumed to be from a rise in the ageing population and lifestyle changes associated with economic development.

Luengo-Fernandez et al. (2013) studied the economic burden of cancer across the European Union. The results revealed that the costs of cancer and health care were EU €126 billion in 2009 and €51.0 billion (40 percent). Cancer treatment expenses equated to  $\notin 102$  per citizen, in Bulgaria  $\notin 16$  per citizen, and Luxembourg  $\notin 184$  per person. A total of  $\notin 42.6$  trillion,  $\notin 9.43$  and  $\notin 23.2$  billion of productivity reductions attributable to early death, lost days and informal care respectively. Nevertheless, lung cancer had the highest economic expense (( $\notin 18.8$  billion, 15 percent), followed by breast cancer ( $\notin 15.0$  billion, 12 percent), colorectal cancer ( $\notin 13.1$  billion, 10.0%), and prostate carcinogens ( $\notin 8.43$  billion, 7 percent).

Lamerato et al. (2006) provided evidence on a retrospective cohort study to evaluate breast cancer recurrence's economic burden from the year 1996 to 2002. The findings determined the cancer patients with occurrence had massive significant charges within the 6th month and 12th month, the post recurrence period compared to the recurrence period, which was the initial phase of 6th month and 12th month. The mean for monthly charges and quarterly charges for continuing care were greater during the post recurrence periods for patients with recurrence. This showed that women with recurrence undertake higher charges compared to patients without recurrence.

In order to analyze the economic effect of cancer in the Brazilian health system between 2010 and 2015, Siqueira et al. (2017) analyzed retrospective data to forecast the effects until 2020. The findings showed that premature cancer mortality had a major effect on economic performance. The projected cost fully in association with the exponential growth in 2010 to 2015 amounted to INT\$ 59.7 billion in 2015. The cost of mortality was 63.0% of the total costs, while the direct cost and morbidity cost was 20.0% and 17.0% respectively. The health expenditure was estimated at 9.5% of GDP and the average cancer costs were estimated at 1.7% of GDP per year.Costs of cancer were expected to reach INT\$ 81 billion by 2020.

Aljunid et al. (2010) carried out a study to predict the clinical and economic burden of disease attributable to HPV from January 2007 to December 2008 in Malaysia. The findings indicated an estimated 4,696 new cases of cervical cancer yearly and 1,372 cases of precancerous lesions. Total direct costs and further indirect costs due to loss of productivity were estimated to be RM 39.2 million and RM 12.4 million. Moreover, it was predicted that 4,199 cases and 3,804 cases could be prevented using the bivalent vaccine and quadrivalent vaccine respectively. The number of yearly cases was estimated to be the same for bivalent vaccine but a reduction of 1,721 cases was estimated for quadrivalent vaccine. The treatment costs for bivalent vaccine and quadrivalent vaccine was RM45.4 million and RM42.9 million respectively. As a result, cervical cancer's clinical and economic burden and precancerous lesions could be reduced through vaccination against HPV 16/18 in Malaysia. The massive potential economic benefit was determined using the bivalent vaccine in preference to the quadrivalent vaccine.

Lee et al. (2015) examined the economic burden of cancer in Korea from 2000 to 2010. The data was collected from national health insurance claims data and information from Statistics Korea. The findings indicated an increased economic burden of cancer from US\$ 11,424 to US\$ 20,858 million within the period studied. The spending on colorectal, thyroid, breast, liver and stomach cancer increased from 2000 to 2010. A decline on the share of mortality cost in the total burden from 71.0% to 51.0% for colorectal, thyroid, breast and prostate cancers was observed.

Oliveira et al. (2018) conducted a population-based cost study to determine the economic burden of cancer care in Canada from year 2015 to year 2012. The finding indicated a steady growth on the costs of cancer care during the period of analysis from \$2.9 billion in 2005 to \$7.5 billion in 2012. The costs mainly rose for hospital-based care. The expenditure for health care services, chemotherapy and radiation therapy peaked during the studied periods. The estimated costs were higher than the actual costs encountered in the Economic Burden of Illness in Canada 2005–2008 report except for that of the year 2005 and the year 2006.

# 2.4 Review of Past Studies on Empirical Findings on Impact of QOL on Cancer2.4.1 Review of Past Studies on Impact of QOL on Cancer based on PrimaryResearch

Fenn et al. (2014) demonstrated a study to differentiate the relationship between the financial problems related to cancer and self-reported quality of life by analyzing the data collected from the worldwide, population-based study. The findings showed a significant indicator of quality of life for the following variables such as age, income, insurance status and total household income. The study also defined poor quality of life in relation to the huge expense of cancer treatment, particularly in the areas of survivors who reported "a lot" financial problems (8.6 percent) compared to those who do not have financial difficulties (69.6 percent) in terms of their physical health , mental wellbeing and social life. In the multivariable analysis, however, the amount

of financial stress incurred by cancer was inversely associated. The bivariate analyzes found to be significant despite the independence of all sociodemographic variables. Higher financial losses due to cancer care expenses were the key independent variables for predicting the reduced quality of life of survivors of cancer.

Bloom et al. (2004) demonstrated a study on young breast cancer survivors' quality of life. The findings showed that 92.0% of the patients graded good or excellent health rates whereas 10.0% of the patients graded their health rate getting worse. Moreover, there were significant enhancement in surgical signs, body outlook, worry about the coming years, patient-physician communication, irritation of treatment, and all SF-36 measures except for general health. A decline in emotional support and social networking can clearly be observed. Followed by no apparent changes in employment status, marital or partner status, sexual activity, sexual problems, self-esteem, and attendance at religious services or prayer frequency. Lesser chronic situations determined a high mental quality of life and a slow decline in emotional support. In contrast, cancer-free patients enjoyed good health with the enhancement of quality of life.

Meisenberg et al. (2015) carried out a convenience-sample survey to determine patient attitudes towards the cost of illness in cancer care in Annapolis, Maryland. The data was collected from the infusion clinic and radiation oncology clinic at a regional multispecialty cancer center. The study focused on the financial well-being scale (8 items, scores ranged from 1-10, with low numbers indicating higher distress). The findings indicated that the average financial distress score was 5.11 which occurred in nearly half of the respondents. This showed that the cancer patients in Annapolis, Maryland experienced high levels of financial hardship.

# 2.4.2 Review of Past Studies on Impact of QOL on Cancer based on Secondary Research

Meneses et al. (2012) conducted a BCEI randomized controlled trial study to determine the effect of economic hardship and burden on quality of life among women with breast cancer in the Southeastern United States. The data was collected from Southeast states and the Wait Control arm of the BCEI. The study focused on physical aspects (fatigue, pain, menopausal symptoms, and change in body image); psychological adjustment, social and family relationships, work and financial concerns; and spirituality and meaning in illness. The findings indicated that the survivors reported a mean of 2.94 for economic hardship items at baseline and a mean of 2.25 for economic burden items at the 6<sup>th</sup> month.

## 2.5 Review of Past Studies on Empirical Findings on Work Productivity

Lerner et al. (1999) used a self-reported questionnaire to evaluate the difficulty in task performing and role demands as well as productivity loss due to missed work in Baltimore, Maryland. The data was collected through phone interviews and indepth interviews with patients who suffered from migraine headache. With the use of previous concepts (disability, inability or limitation), the questionnaire was developed as Migraine Work and Productivity Loss Questionnaire (MWPLQ). The finding indicates that the MWPLQ was an advanced method compared to current available methods as it addressed two main components to evaluate work productivity, which were, diminishment of job efficiency and loss of time.

Malaguarnera et al. (2013) demonstrated a prospective clinical study to examine chemotherapy's effect along with capecitabine in patients with colorectal cancer on work productivity and everyday tasks in Catania, Italy. The finding indicated that a rising in absenteeism after 1 cycle, 6 cycles and at follow-up. However, there is no significant differences between presenteeism, work productivity loss and everyday activity impairment. Followed by a negative consequence for job performances. On the other hand, Giulia Malaguarnera also joined the study related to breast cancer by Vacante et al. (2013). The finding indicated no significant change in absenteeism, presenteeism, loss in work productivity and daily task impairment after 1 and 6 cycles compared with baseline.

Cleeland et al. (2014) carried out a cross-sectional patient reported outcome study to determine the work productivity in patients receiving treatments in the form of first-line hormonal therapy, chemotherapy and/or targeted therapy. The findings indicated that 38.1 percent of the patients were employed, 20 percent experienced impairment which caused missed work time; 30 percent experienced impairment during work and 40 percent suffered work impairment. Overall, a mean of 7.3 hours was missed per week. Patients who experienced fatigue and reduced sexual desire had greater impairment in daily tasks and quality of work.

## 2.6 Review of Past Studies on Empirical Findings on Psychological Impact of Cancer Treatment

Kent et al. (2013) presented a cross-sectional study that determined the relationship between cancer survivors and the act to receive treatment based on financial ability in the year 2010 in the United States. The findings revealed that 8.0% missed a doctor's appointment, 5.0% went without medication and 4.0% took less than the prescribed amount within a period of 12 months. Cancer-related financial problems were disproportionately represented in young cancer members of a minority group and in survivors who had a massive treatment burden and may contribute to survivors forgoing or delaying medical care after cancer.

Chino et al. (2014) carried out an observational, cross-sectional and surveybased study on self-reported financial hardship and satisfaction with care from June 2010 to May 2011. Overall, the results revealed a devastating economic burden for 47 percent of cancer patients. A high financial economic burden was correlated with dissatisfaction on different general factors, such as healthcare, the technical quality of cancer care delivery and financial aspects of healthcare. The massive economic burden, however, was not correlated to patient satisfaction in terms of accessibility and comfort, interaction, interpersonal behavior or time spent with a doctor.

Zafar et al. (2013) carried out a pilot study to determine the impact of health care costs on well-being and treatment among the cancer patients studied from June 2010 to May 2011. The study focused on evaluating the differential effect of financial distress on decision making in terms of out-of-pocket spending, subjective financial costs and well-being and quality of care across the continuum of cancer treatment. The findings indicated that a total of 20.0% less than prescribed medication, 19.0% filled part of a prescription, 24.0% did not fill prescriptions, 7.0% avoided procedures, 9.0% avoided tests, 7.0% spread out appoints and 4.0% skipped appointments by the cancer patients in order to cope with the spending on treatment.

## 2.7 Concluding Remarks

The general components of cancer costs are out-of-pocket expenses, subjective financial burden, well-being and quality of care. In general, measurement of the cancer costs are human capital approach and friction approach. However, there are some different measurements for productivity loss such as the Standard GBD approach and the Washington Panel approach to tackle the patients' loss in monetary value. Moreover, propensity scoring techniques and Likert scale are used to measure for financial distress and quality of life.

The different results obtained from the past studies are due to several indicators and techniques. Most of the cancer patients with reoccurrence and without insurance experienced higher burdens and distress. The massive burden of cancer costs might lead to treatment forgoing or delaying treatment, avoided procedures and skipping appointments to reduce spending on treatment costs especially from low-income patients. There is also a finding that indicates a mean of 2.94 of economic hardship items at baseline and 2.25 economic burden items at the 6th month. A significant relationship exists between productivity loss and the cancer-related premature mortality; hence, it showed that productivity costs provide an alternative perspective on the cancer burden that brings value to the cancer control policy decisions. Other than that, only 38.1 percent of the patients were employed or did not affected during diagnosis; followed by, no significant change or rise in absenteeism, presenteeism, loss in work productivity and daily task impairment after 1 and 6 cycles compared with baseline.

The rising cancer rates in ASEAN was presumed to be due to a rise in the ageing population and lifestyle changes related to economic development. A high mental quality of life was marked by less chronic situations and a slow decline in emotional support Increased financial burden as a result of cancer care costs was the most valid independent variable in predicting poor quality of life among cancer survivors.

No	Author(s)	Data and Variables	Met	hodology and Measurement		Findings
1	Kimman et al. (2012)	<ul> <li>Design: Panel data</li> <li>Sample period: 2008</li> <li>Sample size: 571 million of ASEAN population</li> <li>Data sources: World Bank, World Health Organization (WHO), GLOBACAN 2008</li> <li>Country: All ASEAN countries such as Brunei, Cambodia, Indonesia, Laos, Malaysia, Myanmar, Philippines, Singapore, Thailand and Vietnam</li> </ul>	• * * * •	Methodology: Population estimates Disability adjusted life years (DALYs) Standard GBD approach Measure: Burden of cancer measured by DALYs, population age distribution on cancer and mortality	•	The findings indicate highest burden of cancer in terms of DALYs lost was Laos, Vietnam and Myanmar; followed by the lowest in Brunei, Singapore and Philippines. Females highly claimed on breast cancer, cervix cancer and lung cancer; male patients claimed on liver and lung cancer. Age and mortality rate were key findings that showed huge impact on the study; rise on ageing of populations and changes in lifestyle in related with development of economy.
2	Ekwueme et al. (2014)	<ul> <li>Design: Time series</li> <li>Sample period: 2008-2011</li> <li>Sample size: 6722 cancer survivors (all sites)</li> <li>Data sources: MEPS Experience with Cancer Survivorship Survey</li> <li>Country: United States</li> <li>Variables: total expenditures, source of payments, service type, per capita mean annual lost productivity, source of productivity loss</li> </ul>	•	Methodology: Multivariate logistic regression Measure: Lost productivity measured by inability to work, missed workdays, additional spent in bed and valued with 2011 median wage, change in work, inability to perform physical tasks required by job, mental tasks required by job, feeling less productivity at work	•	The findings indicate the total annual medical expenditures of the cancer survivors were estimated at \$4,187 more for males and \$3,293 more for females, compared to those without a cancer history. Cancer survivors had greater annual productivity loss (men at \$3,719 vs \$2,260 whereas women at \$4,033 vs \$2,703). A third of survivors, cancer and lasting and late effects of treatment interfere with usual daily activities outside of work. 10% of survivors in this study aged lesser than 65 years and uninsured; thus, likely to incurred larger personal financial burden.
3	Guy et al. (2013)	• Design: Panel data	•	Methodology: Multivariable	•	The findings showed that there was an annual
				regression		excess economic

Table 3.1 The summary of literature review

No	Author(s)	Data and Variables	Me	thodology and Measurement		Findings
No	Author(s)	<ul> <li>Data and Variables</li> <li>Sample period: 2008-2010</li> <li>Sample size: 4960 cancer survivors (all sites)</li> <li>Data sources: MEPS Experience with Cancer Survivorship Survey</li> <li>Country: United States</li> <li>Variables: Direct medical costs, indirect morbidity costs and economic</li> </ul>	Me:	thodology and Measurement Sensitivity analysis <b>Measure:</b> Lost productivity measured by inability to work, missed workdays, additional spent in bed and valued with 2011 median wage; OOP expenditure		Findings burden of the cancer patients that are recently diagnosed. The economic burden of cancer patients at age of 18 to 64 years old and 65 years old were \$16,213 and \$16,441 respectively. Nevertheless, the annual excess burden among the previously diagnosed cancer patients was \$4,427 and \$4,519 at the age of 18 to 64 years old and 65 years old accordingly.
4	Guy et al. (2014)	<ul> <li>burden</li> <li>Design: Panel data</li> <li>Sample period: 2008-2011</li> <li>Sample size: 1464 cancer survivors (all sites)</li> <li>Data sources: MEPS Experience with Cancer Survivorship Survey</li> <li>Country: United States</li> <li>Variables: Direct cost (OOP, private health insurance, Medicaid and other sources, ambulatory care, prescription medications and other services) and indirect morbidity cost (employment disability, missed workdays and additional days spent in bed)</li> </ul>	•	Methodology: Statistical software Stata version 13.0 Logistic regression Generalized linear model with a gamma distribution and a log link Multivariable logistic regression Sensitivity analysis Measure: OOP expenditure	•	The findings indicated the yearly adjusted out- of-pocket spending for the adults survivors of cancer diagnosed at the age of 15-39 years was \$765 (2011 US dollars) compared with the adults patients without a cancer history at \$686.
5	Guy et al. (2015)	<ul> <li>Design: Panel data</li> <li>Sample period: 2008-2012</li> </ul>	• * *	Methodology: Descriptive statistics Multivariate logistic regression models	•	The findings indicate that the cancer survivors were more favorable to report a

Table 3.1: The summary of literature review (continued)

No	Author(s)	Data and Variables	Me	thodology and Measurement		Findings
No	Author(s)	<ul> <li>Data and Variables</li> <li>Sample size: 4271 cancer survivors (all sites)</li> <li>Data sources: MEPS Experience with Cancer Survivorship Survey</li> <li>Country: United States</li> <li>Variables: OOP burden towards any healthcare services such as coinsurance, copayments and deductibles</li> </ul>	Met	thodology and Measurement Stata version 14.0 Measure: Total annual OOP spending on healthcare > 20% of annual income OOP payments		Findings massive out-of- pocket burden at 4.3% compared to the cancer patients without a cancer history at 3.4%.
6	Luengo- Fernandez et al. (2013)	<ul> <li>Design: Population-based study</li> <li>Sample period: 2008</li> <li>Sample size: 50994 cancer survivors (all sites)</li> <li>Data sources: Country-specific aggregate data from international sources, including WHO, the Organization for Economic Co-operation and Development, the Statistical Office of the European Communities (EUROSTAT) national ministries of health and statistical institutes</li> <li>Country: All European Union countries such as Austria, Belgium, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany,</li> </ul>	• * * * * • •	Methodology: Population- based cost analysis OLS univariate regression analyses RESET test and link test Breuch-Pagan test Sensitivity analysis Stata (version 12.1) Measure: Loss productivity measured by inability to work, missed workdays of sickness	•	The results revealed that the costs of cancer and health care were $EU \in 126$ billion in 2009 and $\in 51 \cdot 0$ billion (40 percent). Cancer treatment expenses equated to $\in 102$ per citizen, in Bulgaria $\in 16$ per citizen and in Luxembourg $\in 184$ per person. A total of $\in 42 \cdot 6$ trillion, $\in 9 \cdot 43$ and $\notin 23 \cdot 2$ billion dollars of reductions in productivity attributable to early death, lost days and informal cares respectively. Nevertheless, lung cancer had the highest economic expense (( $\in 18.8$ billion, 15 percent), followed by breast cancer ( $\in 15 \cdot 0$ billion, 12 percent), colorectal cancer ( $\in 13 \cdot 1$ billion, 10%), and prostate carcinogens ( $\in 8 \cdot 43$ billion, 7 percent).

Table 3.1: The summary of literature review (continued)

No	Author(s)	Data and Variables	Methodology and Measurement	Findings
		Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Poland, Portugal, Romania, Slovakia, Slovenia, Spain, Sweden,UK • Variables: morbidity, mortality, health care costs and productivity loss		
7	Fenn et al. (2014)	<ul> <li>Design: Cross- sectional interview study, multistage sample design involving stratification and clustering techniques</li> <li>Sample period: 2010</li> <li>Sample size: 2108 cancer survivors (all sites)</li> <li>Data sources: Data from 2010 National Health Interview Survey (NHIS)</li> <li>Country: United State</li> <li>Variables: Cancer-related financial problem and quality of life</li> </ul>	<ul> <li>Methodology:</li> <li>Multivariate analysis</li> <li>Bivariate analyses</li> <li>Binary logistic regression model</li> <li>Measure: Cancer related financial problems and their effects on quality of life</li> </ul>	<ul> <li>The findings showed a significant indicator of quality of life for the following variables such as age, income, insurance status and total household income.</li> <li>The study also defined poor quality of life in relation to the huge expense of cancer treatment, particularly in the areas of survivors who reported "a lot" financial problems (8.6 percent) compared to those who do not have financial difficulties (69.6 percent) in terms of their physical health , mental wellbeing and social life.</li> <li>In the multivariable analysis, however, the amount of financial stress incurred by cancer was inversely associated. The bivariate analyzes found to be significant despite the independence of all sociodemographic variables.</li> <li>Higher financial losses due to cancer care expenses were the key independent variables for predicting the reduced quality of life of survivors of cancer.</li> </ul>

Table 3.1: The summary of literature review (continued)

No	Author(s)	Data and Variables	Me	thodology and Measurement		Findings
<u>No</u> <u>8</u>	Author(s) Bloom et al. (2004)	<ul> <li>Data and Variables</li> <li>Design: Person interview with population- based sample</li> <li>Sample period: 5 years after diagnosis</li> <li>Sample size: 185 omen breast cancer women patients</li> <li>Data sources: Greater Bay Area Cancer Registry Report, Tumor registry data</li> <li>Country: California, USA</li> <li>Variables: Physical domain, psychological domain, social domain and spiritual domain</li> </ul>	•	Methodology and Measurement Methodology: McNemar's test Population based sample Multivariate model change in the SF-36 physical and mental components scale Measure: Effect on quality of life	•	The findings showed that 92% of the patients graded good or excellent health rate whereas 10% of the patients graded their health rate getting worst Significant enhancement in surgical signs, body outlook, worry about the coming years, patient–physician communication, irritation of treatment and all of the SF-36 measures except for general health. A decline in emotional support and social networking; no obvious changes in employment status, marital or partner status, sexual activity, sexual problems, self-esteem and attendance at religious services or frequency of prayer. A high mental quality of life was determined by lesser chronic situations and a slow declined in emotional
9	Drolet et al. (2005)	<ul> <li>Design: Population-based study, random sample</li> <li>Sample period: 1996-1997</li> <li>Sample size: 646 breast cancer patients</li> <li>Data sources: Regic de I;assurance Maladie du Quebec (RAMQ) and Quebec Tumour Registry</li> <li>Country: Province of Quebec</li> <li>Variables: Sociodemographic</li> </ul>	•	Methodology: Log- transformed data Least square method Generalized linear models with loglink and binomial distribution Multivariate analysis Univariate analysis Univariate analysis Measure: Effect of breast cancer on work after diagnosis	•	The findings indicated that work absence constitutes a negative aspect of cancer experience. The cancer- free of breast cancer survivors after one year of diagnosis have higher absence rate from work for 4 weeks and above compared to the healthy women. Followed by the coming three years, cancer-free of breast cancer survivors were no longer experience higher absence rate from work. However, the women that experienced other new cancer events

Table 3.1: The summary of literature review (continued)

No	Author(s)	Data and Variables	Methodology and Measurement	Findings
		work status and health status		<ul> <li>continued to be absence from work or longer periods of time especially receivers of adjuvant chemotherapy.</li> <li>Self-employed or non- union survivors were more likely to report no work absence compared to those that belonging to a union.</li> </ul>
10	Siqueira et al. (2017)	<ul> <li>Design: Descriptive study with retrospective data analysis</li> <li>Sample period: 2010-2015</li> <li>Data sources: Public available databases on hospital admissions (SIH- SUS-Unique Health System) and outpatient care (SIA-SUS) from the public health care system (SUS), mortality and social security (DATAPREV), population data from national database (IBGE)</li> <li>Country: Brazil</li> <li>Variables: Direct cost and indirect cost</li> </ul>	<ul> <li>Methodology:</li> <li>Human capital approach</li> <li>YLLs approach</li> <li>YLDs approach</li> <li>Sensitivity approach</li> <li>Measure: Loss productivity measured by morbidity, disability and premature death using human capital approach</li> </ul>	<ul> <li>The findings showed that the premature cancer mortality had a major effect on economic performance. The projected cost fully in association with the exponential growth in 2010 to 2015 amounted to INT\$ 59.7 billion in 2015. The cost of mortality was 63% of the total costs, while the costs for direct and morbidity were 20% and 17%. The health expenditure was estimated at 9.5% of GDP and the average cancer costs were estimated at 1.7% of GDP per year. Costs of cancer were expected to hit about INT\$ 81 billion by 2020.</li> </ul>
11	Lamerato et al. (2006)	<ul> <li>Design: Retrospective cohort study</li> <li>Sample period: 1996-2002</li> <li>Sample size: 1616 breast cancer patients</li> <li>Data sources: Midwestern healthcare system and estimated from patients charges</li> <li>Country: Detroit Michigan</li> </ul>	<ul> <li>Methodology:</li> <li>Statistical testing</li> <li>Paired t test</li> <li>Linear regression analysis</li> <li>Kaplan-Meier method</li> <li>Precurrence and postcurrence analyses</li> <li>Log- transformed approach</li> <li>Charlson comorbidity index</li> <li>Measure: Burden of cancer- related costs on</li> </ul>	• The findings determined the cancer patients with occurrence had massive significant charges within the 6 <sup>th</sup> month and 12 <sup>th</sup> month, the period of postrecurrence compared to the period of prerecurrence which was the initial phrase of 6 <sup>th</sup> month and 12 <sup>th</sup> month. The mean for monthly charges and

Table 3.1: The summary of literature review (continued)

No	Author(s)	Data and Variables	Methodology and Measurement	Findings
		• Variables: Patients with and without recurrence	prerecurrence and postrecurrence patients	quarterly charges for continuing care were greater during the postrecurrence periods for patients with recurrence. This showed that women with recurrence undertake higher charges.
12	Hanly and Sharp (2014)	<ul> <li>Design: Time series</li> <li>Sample period: 2005-2009</li> <li>Data sources: WHO cancer mortality database, National</li> <li>Employment Survey 2009, Quarterly National</li> <li>Household Survey, Central Statistics Office and World Standard Population</li> <li>Country: Ireland</li> <li>Variables: Lost productivity costs and premature mortality cost</li> </ul>	<ul> <li>Methodology:</li> <li>Human capital approach</li> <li>Proxy good approach</li> <li>Estimation of YPPLL</li> <li>Sensitivity analyses</li> <li>Measure: Cost of lost productivity due to premature cancer- related mortality</li> </ul>	The findings indicated that a significant relationship between the productivity loss and the cancer- related premature mortality. There was higher in the premature mortality cost for male patients whereas a reflection of higher wages and rates of female workforce. The productivity costs conducted in this study provided evidence that it was an alternative perspective on the cancer burden that value to the cancer control policy decisions.
13	Pearce et al. (2018)	<ul> <li>Design: Population-based cross-country cost analysis study</li> <li>Sample period: 2012</li> <li>Sample size: 3011 million of BRIC population</li> <li>Data sources: GLOBACAN 2012</li> <li>Country: Brazil, Russian Federation, India, China and South Africa</li> <li>Variables: Productivity cost, value of potential time in</li> </ul>	<ul> <li>Methodology:</li> <li>Human capital approach</li> <li>Friction cost approach</li> <li>Washington Panel approach</li> <li>Willingness to pay approach</li> <li>Sensitivity analyses</li> <li>Measure: Productivity losses due to premature mortality</li> </ul>	The overall cost of productivity losses in BRICS countries as a result of the premature cancer mortality was \$46.3 billion, which represented 0.33 percent of the combined domestic gross product. China suffered the largest total loss of productivity at \$28 billion, with the highest expense of \$101,000 per cancer death in South Africa. For Brazil, the Russian Federation and South Africa, total productivity losses were highest for lung cancer. Followed by

## Table 3.1: The summary of literature review (continued)

No	Author(s)	Data and Variables	Met	thodology and Measurement		Findings
No 14	Author(s) Aljunid et al. (2010)	<ul> <li>Data and Variables <ul> <li>workforce,</li> <li>friction period,</li> <li>years of</li> <li>productive life</li> <li>lost between</li> <li>cancer death and</li> <li>pensionable age</li> </ul> </li> <li>Design: <ul> <li>Burden of</li> <li>disease study,</li> <li>retrospective</li> <li>study, cross-sectional</li> </ul> </li> <li>Sample period: <ul> <li>2007-Dec 2008</li> </ul> </li> <li>Sample size: <ul> <li>444 cancer</li> <li>patients</li> </ul> </li> <li>Data sources: <ul> <li>WHO,</li> <li>GLOBACAN</li> </ul> </li> </ul>	Met	Methodology: Prevalence- based model univariate regression sensitivity analyses Measure: Burden of disease, potential costs and consequences of HPV vaccination	•	Findingsliver cancer in Chinaand India under lip andoral cavity cancers.The finding indicatedthat an estimated 4,696prevalent cases ofcervical cancer yearly.1,372 prevalent cases ofprecancerouslesionsalong with a total directcostsand furtherindirect costs owing toloss productivity at RM39.2 million12.4millionrespectively.Prevention cases for
15	Dahl et al. (2017)	<ul> <li>Sample size: 444 cancer patients</li> <li>Data sources: WHO, GLOBACAN database and Malaysian national data sources</li> <li>Country: Malaysia</li> <li>Variables: Direct cost of inpatient care and outpatient care</li> </ul>	•	consequences of HPV vaccination	•	indirect costs owing to loss productivity at RM 39.2 million and RM 12.4 million respectively. Prevention cases for cervical cancer cases were predicted at 4199 cases and 3804 cases for bivalent vaccine and quadrivalent vaccine and quadrivalent vaccine and quadrivalent vaccine accordingly at a steady state. The number of cases remained the same for bivalent vaccine but a reduction of 1721 cases under vaccination with quadrivalent vaccine yearly. The treatment costs for bivariate vaccine and quadrivalent vaccine were RM45.4 million and RM42.9 million respectively. A reduction on the clinical and economic burden of cervical cancer and precancerous lesions through vaccination against HPV 16/18 in Malaysia. The massive potential economic benefit was determined using the bivalent vaccine in preference to the quadrivalent vaccine. The finding indicated the productivity loss due to the diagnosis

Table 3.1: The summary of literature review (continued)

No	Author(s)	Data and Variables	Met	thodology and Measurement		Findings
		• Sample period: 1992-1996	*	Quadratic curve approximation		within the 13 studied years was estimated to
		<ul> <li>Sample size: 2010 cancer patients</li> <li>Data sources: Norwegian Cancer Registry and Event Database of Statistics Norway</li> <li>Country: Norway</li> <li>Variables: Productivity cost and income</li> </ul>	•	Regression modelling Statistical analyses such as sensitivity analysis, novel analysis <b>Measure:</b> Estimated life-long income loss associated with productivity loss		102,600 $\in$ per case, with 95% CI (88,500, 116,700). The life-long estimate was 119,200 $\in$ , CI (95,400, 155,600). The national productivity loss in yearly was estimated 179,900,000 $\in$ or 58,200 $\in$ per case. Patients below 65 years old that were still being diagnosed were claimed at an estimated amount of 94,300 $\in$ per case. The estimated life-long productivity loss highly relied on age at diagnosis.
16	Lee et al. (2015)	<ul> <li>Design: Time series</li> <li>Sample period: 2000-2010</li> <li>Data sources: National health insurance claims data and information from Statistics Korea</li> <li>Country: Korea</li> <li>Variables: Direct, morbidity and mortality cost</li> </ul>	•	Methodology: Cost of illness (COI) Human capital approach Measure: Direct morbidity and mortality cost, monetary value of productivity loss based on current wage	•	The finding indicates an increase of economic burden of cancer within the periods studied at US\$11,424 to US\$20,858million. The spending on colorectal, thyroid, breast, liver and stomach cancer increased from year 2000 to 2010. Followed by a decline on the share of mortality cost in the total burden from 71% to 51% for colorectal, thyroid, breast and prostate cancers.
17	Oliveira et	• Design:	•	Methodology:	٠	The finding indicated a
	al. (2018)	<ul> <li>Population-based</li> <li>cost study</li> <li>Sample period:</li> </ul>	*	comprehensive approach Case-control		steady growth on the costs of cancer care during the period of
		2005-2012	·	prevalence- based		analysis from \$2.9 billion in 2005 to \$7.5
		Data sources:     Statistics Canada	*	10-year person- based		billion in 2005 to \$7.5
		and the Canadian Cancer Society	*	Net cost approach		hospital-based care.
		and National	*	Linear interpolation		The expenditure for
		Health Expenditure	•	Measure:		chemotherapy and
		Database (NHEX)		Direct costs of cancer		radiation therapy striking the peak during
		Country: Canada				the studied periods. The estimated costs were
		• Variables:				higher than the actual costs encountered in the

Table 3.1: The summary of literature review (continued)

No	Author(s)	Data and Variables	Me	thodology and Measurement		Findings
		Direct annual cancer cost			•	Economic Burden of Illness in Canada 2005– 2008 report annually except for both year 2005 and year 2006
18	Merola et al. (2018)	<ul> <li>Design: Retrospective cohort study</li> <li>Sample period: 2008-2015</li> <li>Sample size: 90238 patients</li> <li>Data sources: Truven Health Analytics MarketScan Commercial Claims and Encounters (CCAE) with Medicare Supplemental Coordination of Benefits and Health and Productivity Management (HPM) databases</li> <li>Country: United States</li> </ul>	• * * * *	Methodology: Charlson Comorbidity Index (CCI) Statistical Analyses Multivariate zero- inflated Poisson regression Multivariate least square regression StataMP, version 14.1 Measure: Costs associated with productivity loss	•	The findings indicated that the different type of treatment had significance predictor of disability benefit use, costs associated with lost productivity. Injecting therapy patients skipped on average 110 working days in one year following diagnosis and had a gross productivity cost of \$18,315. On the other hand, those patients who obtained oral drugs were losing a total of \$14,429 in productivity costs and missed an average of 87 working days a year after their diagnosis.
19	Ezat et al. (2013)	<ul> <li>Design: Cross-sectional study</li> <li>Sample period: June-December 2011</li> <li>Sample size: 160 patients</li> <li>Data sources: Face-to-face interview and review of medical records, European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire C- 30</li> <li>Country: Malaysia</li> <li>Variables: Criteria, age more than 18, confirmed diagnesis of</li> </ul>	• * * * * * * * * * * * •	Methodology: Effectiveness estimates on life expectancy Life years saved (LYS) QALYs Resource utilization and cost data Sensitivity analysis Cost estimates Economic burden of CRC management Effectiveness estimates Cost effectiveness analysis Incremental cost effectiveness Measure: Comparation of cancer cost of CRC and cost effectiveness of cetuximab and bevacizumab	•	The finding indicated The result reveals the costs at Stage I RM13,623 (12,467- RM14,777) Stage II RM19,753 (RM16,734- RM23,520), Stage II RM24,972, and Stage IV RM27,163 (RM23,192- RM31,133) Stage I RM24,972 (RM20,291- RM29,654). Cetuximab&bevacizuma b incremental costs were respectivelyRM20,556,4 && RM7,557,953, based on the estimated 2671 new CRC cases. Compared to conventional chemotherapy, the rates were at 50 percent at stage III and stage IV. The incremental cost of cetuximab &bevacizumab per quality adjusted lifetime was RM38,869 &RM14,290;

Table 3.1: The summary of literature review (continued)

No	Author(s)	Data and Variables	Methodology and Measurement	Findings
	Vabroff at	colorectal cancer for at least 6 months, agree to participate and no mental illness	MALD	<ul> <li>considered more cost- effective than cetuximab.</li> <li>The cost-effectiveness was sensitive to the percentage of the late stages of CRC. Besides that, both types of monoclonal antibody were considered cost effective based on WHO's criteria with 3 times lesser of GDP.</li> </ul>
20	Yabroff et al. (2005)	<ul> <li>Design: Population-based study, nested case-control</li> <li>Sample period: 1995-1998</li> <li>Data sources: Surveillance, Epidemiology and End Results (SEER)- Medicare</li> <li>Country: United States</li> <li>Variables: Age, gender, 5- year age strata, phase of care, patient time costs, category of medical services</li> </ul>	<ul> <li>Methodology:</li> <li>Convenience sample</li> <li>Estimated Time</li> <li>Systematic estimates of patient time</li> <li>Patient Time Costs (estimated patient time spent travelling to, waiting for and receiving care for each service category)</li> <li>Human capital approach</li> <li>Sensitivity Analysis</li> <li>Measure: Patient's time costs measured by category of relevant medical services and estimated patient time spent travelling to, waiting for and receiving care for each service category</li> </ul>	<ul> <li>The findings indicated the net patient time costs for the 3 phases of colorectal cancer care averaged \$4592 (95% confidence interval CI \$4427- 4757) and \$2788 (95% CI \$2614- 2963) over the 12 months of the initial and terminal phase respectively and followed by \$25 (95% CI:\$23-26) per month in the continuing phase of care. There were more than two thirds of these estimates accounted for hospitalization. Besides that, patient time costs such as direct medical costs were at 19.3%, 15.8% and 36.8% in the initial phase, continuing phase and terminal phase of care</li> </ul>
21	Chang et al. (2004)	<ul> <li>Design: Retrospective matched-cohort control study</li> <li>Sample period: 1990-2000</li> <li>Sample size: 603 brain, colorectal, lung, ovarian, pancreatic, prostate or non- Hodgkin's lymphoma cancer survivors</li> <li>Data sources: National, MarketScan CCAE, Medicare, Health</li> </ul>	<ul> <li>Methodology:</li> <li>International Classification of Diseases (9<sup>th</sup> revision, clinical modification [ICD9-CM]) diagnoses</li> <li>Medstat's Disease Staging algorithm</li> <li>CHarlson comorbidity index (CCI)</li> <li>Descriptive analysis, X<sup>2</sup>tests</li> <li>Two-sided t test</li> <li>Regression- adjusted total direct costs per month</li> <li>Covariate</li> <li>Ordinary Least Squares model with natural logarithmic</li> </ul>	<ul> <li>The average health care costs for prostate cancer and pancreas, ranging between \$2,187 and \$7,616 respectively. Health expenses were \$329 a month and cancer employees were affected by indirect morbidity of \$950, with an annual average loss of 2.0 workdays and 5.0 STD days. Relative to controls, survivors of cancer patients have also reported higher monthly absenteeism (\$373 vs \$101) and higher monthly average short-term impairment</li> </ul>

Table 3.1: The summary of literature review (continued)

No	Author(s)	Data and Variables	Me	thodology and Measurement		Findings
		<ul> <li>and Productivity Management</li> <li>Country: United States</li> <li>Variables:</li> <li>Age, sex, geographic region, type of health plan, geographic region, CCI, length of follow- up periods and in-hospital mortality</li> </ul>	* * •	transformation of the dependent variable (total direct cost) Smearing estimate Multivariate analysis SAS version 8.2 software <b>Measure:</b> Health care cost and indirect morbidity costs; day absent from work and short-term disability		(\$698 vs \$25) days. On the other hand, the number of days missed in the caregiver monthly (2.2, vs. 1.4) associated with higher spending (\$161 versus \$255).
22	Dowling et al. (2013)	<ul> <li>Design: Panel study, MEPS design</li> <li>Sample period: 2008-2010</li> <li>Sample size 4960 cancer survivors (all sites)</li> <li>Data sources: National MEPS</li> <li>Country: United States</li> <li>Variables:</li> <li>Age, sex, educational attainment, race or ethnicity, comorbid condition, demographic, health status, employment, health care use and medical expenditure</li> </ul>	• * * * * * * * * •	Methodology: Analytic sample Descriptive statistics Multivariate logistic regression SUDAAN Wald statistics Measure: Employment limitations in work, housework or school because of health	•	The results showed the lower job rates and higher limitations in the workforce, housework or school for cancer survivors aged 18-64 years old with chronic disease. Compared to those with neither cancer nor chronic illness; neither heart disease nor diabetes, or diabetes, specific reports for cancer site reports for cancer site reports for cancer site reports for any constraints in work, housework and school (8.8% -17.5%). The number of people lacking cognitive function and cognitive constraints ranged from 4.7 to 11.7 percent and 3.4 to 8.5 percent.
23	Jayadevap pa et al. (2010)	<ul> <li>Design: Observational prospective cohort study</li> <li>Sample period: 2002-2005</li> <li>Sample size 512 prostate cancer patients</li> <li>Data sources: Urology clinics of an academic medical centre and the Veterans Administration Medical Center</li> </ul>	• * * * * *	Methodology: Baseline Charlson comorbidity index by using ICD9 codes Pilot test Human capital approach HRQoL by using Medical Outcome Study Short Form (SF- 36) UCLA Prostate Cancer Index (PCI) T-test Chi-square analysis Criterion validity	•	The findings indicated that the out-of-pocket spending on receiving prostatectomy and radiation at 24 month followed-up were \$330 and \$661 respectively. The average of indirect costs and time costs at 12 months were \$256 and \$341 respectively for prostate cancer patients whereas the cancer patients that received radiation

Table 3.1: The summary of literature review (continued)
No	Author(s)	Data and Variables	Me	thodology and Measurement		Findings
		Variables:	*	Face validity		therapy were \$380 and
		Age, ethnicity,	*	Interclass correlation		\$ 187 accordingly.
		charlson		coefficients (ICC)		
		comorbidity,	*	ANOCA		
		education,	*	Propensity scores		
		marital status,	**	Estimates of standard		
		income level,	.•.	error		
		hospital	***	Linear mixed effect		
		spending, signs	*	Variance and		
		and clinical stage	•	covariance'		
		and chinical stage	•*•	Log-linear models		
			*	Bonferroni correction		
			*	Simple mean		
			*	statistical imputation		
				method		
			•	Measure:		
				OOP expenditures		
				(medical and		
				nonmedical costs); time		
				and indirect costs were		
				measured as travel		
				time, number of missed		
				imputed indirect costs		
24	Wan et al	Design:	•	Methodology:	•	The reported total
27	(2013)	Design     Design	*	ICD-9-CM	•	annual cost to survivors
	(2010)	<ul> <li>Reflospective</li> <li>matched-cohort</li> </ul>	*	ENROLID		of breast cancer.
		study	•	Charlson Comorbidity		metastatic breast cancer
		• Sample period:		Index (CCI)		survivors and controls
		2005-2009	*	Standard deviations		for total per-capita
		• Sample size	*	Chi-squares test		indirect leave are
		1984 breast	*	T-tests		\$2383, \$1775, and
		cancer survivors	*	Generalized linear		\$1282. However, for
		and 1375 family		models (GLMs) with		EBC, MBC and control,
		members		log link and gamma		the indirect payments
		• Data sources:	*	Lincor regression		disabilities ware
		National	•••	analyses		respectively \$ 6165
		MarketScan	*	SAS version 9.2		\$ 3690 and \$ 558 The
		Ucalth and	*	Inclusion/ Exclusion		costs for caregivers'
		Productivity		criteria		leave were 1075 and
		Management	٠	Measure:		808 dollars for both
		databases		Survivors' indirect		MBC and EBC.
		• Country:		costs (sick leave from		
		United States		absentiseem and short-		
		• Variables:		term disability) and		
		Health insurance		tamily members'		
		plan, baseline		loave and leave under		
		chemotherapy,		Eave and leave under $\mathbf{FML}(\Delta)$		
		chemotherapy				
		use during				
		Iollow-up,				
		Comorbidity				
		Index				

Table 3.1: The summary of literature review (continued)

No	Author(s)	Data and Variables	Methodology and Measurement Findings	
<u>No</u> 25	Author(s) Huntingto n et al. (2015)	<ul> <li>Data and Variables</li> <li>Design: Cross-sectional pilot study</li> <li>Sample period: August 2014- January 2015</li> <li>Sample size 100 multiple myeloma cancer patients Data sources: Philadephia, PA; Academic Medical Center</li> <li>Country: USA</li> <li>Variables:</li> <li>Age, gender, ethnic origin, marital status, household income per year, employment status, change in employment since diagnosis, education, insurance, resident of state with oral parity &amp; driving distance</li> </ul>	<ul> <li>Methodology and Measurement</li> <li>Methodology:</li> <li>COST measure</li> <li>Descriptive statistics</li> <li>Fisher's exact test</li> <li>Wilcoxon rank-sum test</li> <li>Spearman rank correlation</li> <li>Kruskal-Wallis test</li> <li>Linear regression</li> <li>Multicollinearity</li> <li>Multivariate model</li> <li>Adjusted values</li> <li>Stata version 13.1</li> <li>Measure:</li> <li>Financial toxicity by COST measure (score range-0- 44, lower value equals greater burden), self- reported level of financial burden (not at all, minor, moderate significant)</li> <li>Changes in employme nt since diagnosis, including reduction in work hours and increase in work hour</li> </ul>	icate a e of 23 cancer COST rongly use of nditure ntified least a of p was 90 per cvivors below ent of ported ag, 12 ducing , 20 ng the bercent orking
26	Bernard et al (2011)	<ul> <li>Design: Panel study</li> <li>Sample period: 2001-2008</li> <li>Sample size 4243 cancer survivors (all sites)</li> <li>Data sources: National MEPS 2001-2008 (annual)</li> <li>Country: United States</li> </ul>	<ul> <li>Methodology:         <ul> <li>Population mean of burden ratio</li> </ul> <ul> <li>Ratio of aggregate out- of-pocket expenditures to aggregate income</li> <li>ICD-9</li> <li>AHRQ Clinical Classification Software (CCS)</li> <li>Healthcare Cost and Utilization Project Chronic Condition Indicator</li> <li>Consumer Price Index</li> <li>Taylor series linearization of variance</li> <li>Extension and sensitivity tests</li> <li>Measure: OOP burden, high health care total burden of &gt;20% of earnings</li> </ul> </li> <li>Methodology:         <ul> <li>The findings ind that the survivors had to S3881 (2008 dolla annual out-of- p spending. The health care total burden of &gt;20% of earnings</li> </ul> </li> </ul>	licated cancer otal of ars) on pocket high burden cancer with vithout ns. The tes the 0% of

Table 3.1: The summary of literature review (continued)

No	Author(s)	Data and Variables	Me	thodology and Measurement		Findings
<u>No</u> 27	Author(s) Davidoff et al. (2013)	<ul> <li>Data and Variables</li> <li>Design: Retrospective and observational study</li> <li>Sample period: 1997-2007</li> <li>Sample size 1868 cancer survivors (all sites)</li> <li>Data sources: National MCBS 1997 to 2007 (2yrs)</li> <li>Variables: Cancer site, supplement insurance, income as %FPL, assets, age, gender, ethnicity, marital status, education, location, region, HCC count, functional status limitations, attitudes regarding care seeking and cancer treatment</li> </ul>	Me:	thodology and Measurement Methodology: ICD-9-CM Binary indicator for OOP spending Consumer Price Index Medicare and Medicaid HCCs Healthcare Common Procedure Coding System (HCPCS) Bivariate analyses Multivariate models Generalized linear model Marginal probabilities Logistic regression analysis Cross-sectional sampling weights SAS version 9.2 Measure: Total OOP spending and spending for the out-of-pocket >20% of income	•	Findings The findings indicated that the beneficiaries with cancer paid was \$4727 (cumulative 2 years expenditure, 2007 dollars) in out-of- pocket whereas the comparison group paid was \$3209. In addition, the massive out-of- pocket impose burden on 28% of the cancer survivors and 16% of beneficiaries without cancer history.
28	Jacobsen et al. (2012)	<ul> <li>Design: Retrospective and observational study</li> <li>Sample period: 2004-2008</li> <li>Sample size 3918 oral, oral pharyngeal and salivary gland cancer survivors</li> <li>Data sources: National MarketScan CCAE databases</li> <li>Country: United States</li> </ul>	•	Methodology: Propensity scoring techniques Inclusion criteria Charlson Comorbidity Index Descriptive statistics T-test Chi-square test HCPCS CPT-4 ICD-9-CM SAS 9.2 Measure: OOP payments	•	The findings indicated that the annual out-of- pocket spending for survivors with commercial insurance and Medicare were \$2133 and \$785 more than for controls group.
29	Jagsi et al. (2014)	<ul> <li>Design: Longitudinal cohort study</li> <li>Sample period: 2005-2007</li> <li>Sample size 1502 breast cancer survivors</li> <li>Data sources:</li> </ul>	• * * *	Methodology: Modified Dillman Baseline Survey SAS (SAS/STAT User's Guide, Version9.2) Analytic approach Logistic regression model	•	The findings indicate that 65% of the breast cancer survivors paid less than \$2000 on OOP spending, 18% of them paid at \$2001- <\$5000 and 17% of the cancer survivors paid more than \$5000.

Table 3.1: The summary of literature review (continued)

No	Author(s)	Data and Variables	Methodology and Measurement	Findings
		<ul> <li>Los Angeles, CA and Detroit, MI, SEER</li> <li>Country: Metropolitan Los Angeles and Detroit</li> <li>Variables: OOP spending, financing of medical expenses, debt, privations and reported case for personal medical expenses since diagnosis</li> </ul>	<ul> <li>X<sup>2</sup> test</li> <li>Measure: OOP expenditure</li> </ul>	
30	Meisenber g et al. (2015)	<ul> <li>Design: Convenience- sample study</li> <li>Sample size 132 cancer survivors (all sites)</li> <li>Data sources: Single cancer institute neither from the infusion clinic nor the radiation oncology clinic at a regional multispecialty cancer center</li> <li>Country:</li> <li>Annapolis, Maryland</li> <li>Variables:</li> <li>Overall costs to society, personal financial situation and cost of treatment pain</li> </ul>	<ul> <li>Methodology:</li> <li>Generalized linear models</li> <li>Poisson distribution with a log link</li> <li>Stata version 13</li> <li>Measure: In charge Financial Distress or Financial Well- Being Scale (8 items, score range – 1-10, with low numbers indicating higher distress)</li> </ul>	• Average financial distress score was 5.11, nearly half of the respondents reported high levels of financial distress.
31	Davidoff et al. (2015)	<ul> <li>Design: Panel cohort study</li> <li>Sample period: 2008-2010</li> <li>Sample size 2527 cancer survivors (all sites)</li> <li>Data sources: National MEPS- HC 2008 to 2010</li> <li>Country: United States</li> <li>Variables:</li> </ul>	<ul> <li>Methodology:</li> <li>Deterministic model</li> <li>Descriptive analyses</li> <li>Consumer Price Index</li> <li>Wald test</li> <li>Taylor-series linearization</li> <li>Stat 12 software package</li> <li>Measure: Financial hardship measure (financial burden [OOP expenditure divided by unadjusted gross</li> </ul>	• The findings indicated that 18% of cancer survivors reported financial hardship whereas 37% of the uninsured cancer survivors complained on financial distress.

Table 3.1: The summary of literature review (continued)

			-	inouology and measurement		rmungs
		Insurance coverage, medical expenditures, insurance premiums and a wide range of other health- related and socioeconomic components				
32	Chino et al. (2014)	<ul> <li>Design: Observational, cross-sectional and survey-based study</li> <li>Sample period: 2010-2011</li> <li>Sample size 168 cancer survivors (multiple sites)</li> <li>Data sources: Multiple cities and states, Duke University and Health Well Foundation</li> <li>Country: United States</li> <li>Variables: General satisfaction with health care, perceived technical quality of care, interpersonal manner, patient- physician communication, financial aspects of care, time spent with doctors, accessibility and convenience</li> </ul>	• * * * * * * * * * * * * * * * * * * *	Methodology: Patient Satisfaction Questionnaire Short- From (PSQ- 18) Survey-specific 5- point Likert scale Descriptive statistics T test Univariate linear regression Multivariate linear regression Bayesian information criterion Measure: Psychological and subjective financial distress, 5- point likert scale ranging from "not a financial burden at all" to "catastrophic financial burden"	•	The findings indicated a total of 47% of the cancer patients reported catastrophic economic burden, high financial economic burden was associated with dissatisfaction in different general aspects such as health care, technical quality of cancer care delivery and the financial aspects of health care. In addition, the massive economic burden was not in related with patient's satisfaction scores in terms of accessibility and convenience, communication, interpersonal manner, or time spent with doctors
33	Kent et al. (2013)	<ul> <li>Design: Cross-sectional study</li> <li>Sample period: 2010</li> <li>Sample size 1556 cancer survivors (all sites)</li> </ul>	• * * *	Methodology: Complex and multistage sampling framework Multivariate logistic regression (predictive marginals method) Covariate adjustment Statistical Analysis Statistical Analysis	•	The findings indicated there were 8% missed a doctor's appointment, 5% went without medication and 4% took less than prescribed amount based at the period within 12 months. Cancer-related

Table 3.1: The summary of literature review (continued)

No	Author(s)	Data and Variables	Me	thodology and Measurement		Findings
		<ul> <li>Data sources: National NHIS 2010</li> <li>Country: United States</li> <li>Variables:</li> <li>Sociodemographic , clinical and treatment related factors associated with perceived cancer-related financial issues and association between financial problems and forgo or delay healthcare due to costs</li> </ul>	•	callable version of SUDAAN 10.0 <b>Measure:</b> Behavioral, financial problems and forgoing or delaying care		were not only disproportionately represented in young cancer members of a minority group or survivors that had a massive treatment burden, but it may also contribute to survivors forgoing or delaying medical care after cancer.
34	Zafar et al. (2013)	<ul> <li>Design: Pilot study</li> <li>Sample period: June 2010-May 2011</li> <li>Sample size 258 cancer survivors (multiple sites)</li> <li>Data sources: Multiple cities and states, Health Well Foundation and Duke University Medical Center</li> <li>Country: United States</li> <li>Variables: OOP expenses, subjective financial burden and well-being, subjective financial burden and quality of care</li> </ul>	• • • • • • • •	Methodology: Baseline survey Descriptive statistics $X^2$ test Logistic regression Pearson correlations Sensitivity analysis Measure: Behavioral, strategies to cope with the cost of prescription medications and cancer care expenses	•	The findings indicated that a total of 20% less than prescribed medication, 19% filled part of a prescription, 24% did not fill prescriptions, 7% avoided procedures, 9% avoided tests, 7% spread out appoints and 4% skipped appointments by the cancer patients in order to cope with the spending on treatment.
35	Bestivina et al. (2014)	<ul> <li>Design: Cross-sectional survey study</li> <li>Sample period: November 2012- June 2013</li> <li>Sample size 300 cancer survivors (multiple sites)</li> <li>Data sources: Duke Cancer</li> </ul>	• * * * *	Methodology: InCharge Financial Distress/Financial Well-Being Scale Descriptive statistics $X^2$ or Fisher's exact test Univariable analyses Multivariate logistic regression Logistic regression analysis SAS version 9.3	•	The findings indicated that a total of 16% of the cancer survivors reported enormous/ worried financial difficulties.

Table 3.1: The summary of literature review (continued)

No	Author(s)	Data and Variables	Me	thodology and Measurement		Findings
		<ul> <li>Institue and 3 affiliated rural oncology clinics</li> <li>Country: North Durham</li> <li>Variables: Self-reported demographic data, cost-related decision making, objective and subjective financial burden and medication adherence</li> </ul>	•	Measure: Subjective financial distress (IFDFW)		
36	Meneses et al. (2012)	<ul> <li>Design: BCEI randomized controlled trial study</li> <li>Sample period: 6 months</li> <li>Sample size 137 breast cancer survivors</li> <li>Data sources: Southeast states and Wait Control arm of the BCEI</li> <li>Country: Southeastern United States</li> <li>Variables: Physical (fatigue, pain, menopausal, symptoms and change in body image); psychological adjustment, social and family relationships, work and financial concerns; and spirituality and</li> </ul>	• * * * * * * * * * * * • •	Methodology: Quality of life- breast cancer survivors (QOL- BCS) Test-retest reliability Breast Cancer Finances Survey (BCFS) Descriptive analysis Generalized linear mixed models fitted with binomial distributions and logit links and variance/covariance structures GLIMMIX procedure in SAS version 9.2 Structural equation models (SEM)Multivariate normality Comparative Fit Index (CFI) Goodness-of-fit index (CFI) Root mean square error of approximation (RMSEA) Measure: 19 economic burden items related to work and financial hardship	•	The finding indicated that the survivors reported a mean of 2.94: economic hardship items at baseline and 2.25 economic burden items at the 6 <sup>th</sup> month.
37	Lerner et al. (1999)	illness • Design: Self-reported questionnaire; large population -based survey • Sample size 108 patients • Data sources:	• * * * *	Methodology: Telephone interview In-depth interview Population-based sample Interdisciplinary approach Occupational	•	The finding indicates that the MWPLQ is an advance method compared to current available method as it addresses two main components to encounter work
		Migraine		classification method		productivity such as

Table 3.1: The summary of literature review (continued)

No	Author(s)	Data and Variables	Me	thodology and Measurement		Findings
38	Author(s)	<ul> <li>headache clinical trials data collection</li> <li>Country: Baltimore, Maryland</li> <li>Variables: Difficulty getting to work; difficulty working in proximity to environmental triggers of migraine symptoms; difficulty handling in terms of aspects of physical, visual and mental; interpersonal work issues; diminished work quantity, quality and time management and negative aspects of work ability</li> <li>Design:</li> </ul>	• •	Measure: Difficulty in performing work role demands and productivity loss due to missed work	•	diminished on job efficiency and loss of time.
	-era et al. (2013)	<ul> <li>Prospective clinical study</li> <li>Sample period: January 2011 and December 2012</li> <li>Sample size 30 patients with stage III disease</li> <li>Country: Catania, Italy</li> <li>Variables: Absenteeism, presenteeism and work productivity</li> </ul>	* * * * * * * * *	WPAI questionnaire Statistical Analysis Mann-Whitney test Chi-square test SPSS 15.0 <b>Measure:</b> To examine the effect of chemotherapy along with capecitabine in patients with colorectal cancer on work productivity, daily tasks	•	that a rising inducates that a rising in absenteeism after 1 cycle and 6 cycles and at follow-up. There is no significant differences between these 3 components such as presenteeism, work productivity loss and daily task impairment. Negative consequences for job performances. Limitation: limited sample size and lack of comparator
39	Cleeland et al. (2014)	<ul> <li>Design: US-based, multicenter, prospective, observational cohort study</li> <li>Sample period: May 2008 and December 2012</li> <li>Sample size 152 patients with locally recurrent</li> </ul>	•	Methodology: WPAI-Specific Health Program Activity Level Scale HRQoL MDASI ANCOVA model Univariate regression Multivariate regression Pearson correlation coefficients	•	The findings indicate that 38.1 percent of the patients were employed, 20 percent with impairment cause work time missed; 30 percent having impairment during working and 40 percent suffered work impairment.

Table 3.1: The summary of literature review (continued)

No Author	(s) Data and Variables	Methodology and Measurement	Findings
	or metastatic illness • <b>Country:</b> • United States	• Measure: To determine the work productivity in patients receiving treatments as first-line hormonal therapy, chemotherapy and/or targeted therapy	<ul> <li>A mean of 7.3 hours missed per week.</li> <li>Fatigue and reduced sexual desire had greater impairment in daily tasks and quality of work.</li> </ul>
40 Vacante al. (2013	et • <b>Design:</b> Prospective clinical study • <b>Sample period:</b> January 2011 and February 2013 • <b>Sample size</b> 34 patients with metastatic illness; willing to work • <b>Country:</b> Catania, Italy • <b>Variables:</b> Absenteeism, presenteeism and work productivity	<ul> <li>Methodology:</li> <li>WPAI questionnaire</li> <li>Statistical Analysis</li> <li>Mann-Whitney test</li> <li>SPSS 15.0 coefficients</li> <li>Measure: To examine the effect of chemotherapy along with capecitabine in patients with colorectal cancer on work productivity and everyday tasks</li> </ul>	• The findings indicate that no significant change in absenteeism, presenteeism, loss in work productivity and daily task impairment after 1 and 6 cycles compared with baseline.

Table 3.1: The summary of literature review (continued)

## **CHAPTER THREE**

#### METHODOLOGY

## 3.0 Introduction

The theoretical framework that been put forward by past researchers will be discussed, followed by the methodology and findings. A conceptual framework has been developed for this study to quantify the costs of cancer in Sarawak. This chapters also includes the description of population, sampling, questionnaire design, data collection, pilot test and data analysis methods for this study. Lastly, this chapter ends with conclusion.

## 3.1 Theoretical Framework of Burden of Disease of Cancer

### **3.1.1 Human Capital Approach**

Generally, human capital is a factor that contributes to a rise in a worker's productivity in terms of labor economics. In other words, it refers to the collective skills, knowledge and intangible assets that provides economic value to society. The human capital approach is based on the neoclassical economic model. This model assumes a perfect market competition and that income earnings reflect productivity. Moreover, the variables used are time span, forgone activity, paid labor, benefits and fixed payroll costs (Pearce et al., 2014). The following is the possible classification for human capital:

Grammy and Assane (1997) have found that human capital formation positively and significantly contributed to the labor productivity. There was an improvement made for the neoclassical growth model augmented by Mankiw, Romer and Weil (1992) to have a wider measurement on human capital. The approach developed enhance the explanatory power of the model and the speed of conditional income convergence.

Grossman (2000) defined health was widely determined which encountered the longevity and illness-free days within a given period that was both demanded and produced by the consumers. Moreover, health was a choice variable and a source of utility (satisfaction) that interpret income and wealth levels. The consumption of health by the consumers was determined by preference whereas an investment in health was indicated by total amount of available time for market and nonmarket events. In other words, a rise in the stock of health diminished the amount of time lost from the event and monetary value in term of investment. Moreover, there was a positive relationship between initial stock of health and age. These two variables declined as years go by and rise after certain stages of life cycle and at the same time are improved by investment. The death happened when the stock of health declined below the bottom line. The health capital model created by Grossman had its own unique point where the individual can "choose" their length of life. The function was based on household production. He highlighted the law of downward sloping demand function to explain the negative relationship between the quantity of health demanded and the "shadow price".

Becker (2007) found that consumers maximize utility according to the availability of the resources to achieve optimal behaviour. Steps are taken in order to influence the rate of survival at different levels of age. An optimal investment was

determined to lower the mortality rate by using the outcome of the optimization analysis. This provided evidence to quantify the willingness to pay for improvements in probabilities of surviving to different ages which was known as the statistical value of life. Moreover, with a decline in age and interest rates; at the same time, an increase in income showed that the value of life was higher during the concave shape of the period utility function and according to other variables. Becker believed that a decrease in mortality at all ages was the most significant developments in field of economic and social fields during the twentieth century. The findings also indicated that higher survivorship at adult ages endowed greater investment on education and beneficial goods that provide greater benefits and expected return and strike for better future utility. In other words, an increase in the probability of surviving from one disease will lead to an enhancement for other disease in relation with expected benefit. If the survival rates at older ages improved, the survivor rate at earlier ages can improve as well.

# **3.1.2 Friction Cost Approach**

Friction Cost calculates the actual productivity loss during the period when a replacement takes place for the worker. There is an absence of the theoretical foundation for this approach. This model assumes the presence of unemployment in the labor market and the variables used are frequency and length of friction period, value of lost production and macroeconomic consequences (Pearce et al., 2014). The following is the possible classification for friction costs:

Koopmanschap, Rutten, Ineveld and Roijen view (1995) introduced the friction cost method that can minimize the estimated production losses compared to predictions made on the human capital approach. They argued that the real indirect costs were lower than the estimates based on the human-capital approach. This was because of the presence of diminishing returns to labour, internal labour reserves within firms and the condition where the sick employees can catch up the left-out work when they returned to the workplace after a period of absence. As a result, it was determined that the friction cost approach was a better determinant for the economic impact of illness.

#### 3.1.3 Productivity Cost or Loss

Krol and Brouwer (2014) studied a measurement on productivity costs in economic evaluations. The findings indicated that productivity costs should be included in the economic evaluation to ease the decision making for cost and potential savings of healthcare interventions. A recommendation to measure not only productivity costs associated with absenteeism and presenteeism of paid work but also productivity loss associated with unpaid work. The measurement tools such as iPCQ and VOLP to determine the health-related productivity losses. The findings also suggested to apply both the friction cost approach and human capital approach to increase the reliability of the studies.

Bouwmans et al. (2015) made a significant contribution by adoption of economic evaluation for productivity loss. The instrument comprised of three components such as absenteeism (PRODISQ and SF-HLQ); presenteeism (PRODISQ and SF-HLQ) by using Quantity and Quality (QQ) method as well as productivity loss due to unpaid work (SF-HLQ). The finding proved that iPCQ is understandable and concise to the point of quantifying health-related productivity loss.



Figure 3.1: Theoretical Framework of Economic Burden

Source: Witte et al. (2019).

The main definition consists of three fields addressing the following factors: (i) the consumer circumstances arising from increased direct and indirect costs; (ii) the interpersonal reaction resulting from the actions required to deal with the increased costs; and (iii) the coping strategies themselves developed by patients to maintain their medical care while facing increased costs (Altice et al., 2017). Witte et al. (2019) further expanded the grouping as shown in Figure 2 into six subdomains. It was recommended to split the area of material conditions between active' financial spending' (e.g. proportion of health-related expenditure of household income) and the use of inactive' financial resources' (e.g. selling property or saving). Apart from this, there is a clearer difference between direct and indirect financial responses, which

tends to be important for third-party payer systems for complete (approximate) recovery of therapy costs. The 'affect' area continues to reflect the psychological response to elevated cancer-related expenses (e.g., current financial concerns). The renaming of this area as 'psychosocial reactions ' to reflect aspects of the current social environment. Finally, we recommend subdividing potential coping patterns into three subdomains: ' support seeking ' from others (e.g. looking for financial assistance), modifying care plans (' coping care ' e.g. cutting back on prescribed medication) and adjusting one's activity (' coping lifestyle ', e.g. decreasing leisure activities).

## 3.2 Conceptual Framework Related to Economic Burden on Cancer Care

The proposed conceptual framework is shown in Figure 2. The word 'financial toxicity' has been developed as a generic term, describing both 'objective financial burden' and 'subjective financial distress' faced by cancer patients in the United States (Carrera, Kantarjian & Blinder, 2018). In this study, objective financial burden and subjective financial distress are both used to compute for financial toxicity. Apart from this, there is a clearer difference between direct and indirect financial responses, which tends to be important for third-party payer systems for complete (approximate) recovery of therapy costs. The' affect' area continues to reflect the psychological response to elevated cancer-related expenses (e.g., current financial concerns).



Figure 3.2: Conceptual Framework

There is an extended number of patients with more treatment options in response to the growing cost of treatment and longer length of therapy (Azzani et al., 2015). Besides the economic impact of cancer treatment on healthcare systems, there are also determinable economic side effects at the patient level. Studies on the individual financial impact of cancer therapy to date has focused primarily on quantifying subjective financial burden such as out-of-pocket (OOP) spending (Bestvina et al., 2014). In comparison, only in recent years has the qualitative financial impact perceived as the consequence of cost concerns on the individual patient gained attention.

Studies also show that anxiety and stress correlate with a variety of adverse health consequences, both physical and mental, the same goes for individual sideeffects of cancer therapy costs (Zimmerman & Katon, 2005). Patients with severe personal financial distress may adjust their treatment to defray OOP costs, may have poorer health-related quality of life (HRQOL) or even experience lower survival rates (Zafar et al., 2013; Lathan et al., 2016).

## 3.3 Hypothesis Development

There are 13 main hypotheses used to estimate the burden of illness of cancer, focusing on the economic perspective of disease burden among cancer survivors in Sarawak. The sociodemographic variables include ethnicity, age group, education level, employment status, baseline household income and area of residence. However, clinical variables comprise the primary cancer site, cancer stages, family history, treatment pathway, chemotherapy, radiotherapy and surgery. Followed by the variables of work productivity loss such as absenteeism, presenteeism, temporary workforce absenteeism and early retirement were also assessed. The hypothesis of this study is stated as below:

#### **Hypothesis 1:**

H<sub>0</sub>: There is no association between core treatment costs and sociodemographic variables.

H<sub>1</sub>: There is an association between core treatment costs and sociodemographic variables.

## **Hypothesis 2:**

 $H_0$ : There is no association between follow-up costs and sociodemographic variables.  $H_1$ : There is an association between follow-up costs and sociodemographic variables.

# **Hypothesis 3:**

H<sub>0</sub>: There is no association between non-medical costs and sociodemographic variables.

H<sub>1:</sub> There is an association between non-medical costs and sociodemographic variables.

## **Hypothesis 4:**

H<sub>0</sub>: There is no association between financial costs and sociodemographic variables.

H<sub>1:</sub> There is an association between financial costs and sociodemographic variables.

#### **Hypothesis 5:**

H<sub>0</sub>: There is no association between cost of cancer care and clinical variables.

H<sub>1:</sub> There is an association between cost of cancer care and clinical variables.

#### **Hypothesis 6:**

H<sub>0</sub>: There is no association between core treatment costs and clinical variables.

H<sub>1:</sub> There is an association between core treatment costs and clinical variables.

## **Hypothesis 7:**

H<sub>0</sub>: There is no association between follow-up costs and clinical variables.

H<sub>1</sub>: There is an association between follow-up costs and clinical variables.

#### **Hypothesis 8:**

H<sub>0</sub>: There is no association between non-medical costs and clinical variables.

H<sub>1:</sub> There is an association between non-medical costs and clinical variables.

## **Hypothesis 9:**

H<sub>0</sub>: There is no association between financial costs and clinical variables.

H<sub>1:</sub> There is an association between financial costs and clinical variables.

## Hypothesis 10:

H<sub>0</sub>: Cancer treatment does not cause a significant impact on work productivity loss.

H1: Cancer treatment causes a significant impact on work productivity loss.

## Hypothesis 11:

H<sub>0</sub>: There is no association between level of financial toxicity and sociodemographic variables.

H<sub>1:</sub> There is an association between level of financial toxicity and sociodemographic variables.

# Hypothesis 12:

H<sub>0</sub>: There is no association between level of financial toxicity and clinical variables.

H<sub>1:</sub> There is an association between level of financial toxicity and clinical variables.

## Hypothesis 13:

H<sub>0</sub>: There is no relationship between financial toxicity and socioeconomic and clinical variables.

 $H_{1:}$  There is a relationship between financial toxicity and socioeconomic and clinical variables.

## **3.4 Measurement of Variables**

#### **3.4.1 Method to Quantify Productivity Loss**

Loss in productivity is the loss due to early retirement and time off to undergo treatment and can be lifelong. The cost of productivity loss is significantly contributes to the economic analysis which carries on a social context when counting the number of day loses. In economic terms, the loss of productivity associated with cancer is due to morbidity and the cost of premature mortality. The cost of morbidity includes short-term job absences associated with cancer as well as lifelong absences related with the retirement from the workplace. The cost of premature mortality includes the additional life loss directly attributed to the disease and the associated reduction in potential productive capacity. A debate remains on the approapriate method for measuring the value of the disease-related costs of productivity. From the thoeretic point of view, there are two approaches used to measure the loss of productivity, that is the human capital approach and the friction cost approach.

## **3.4.2 Computation of Productivity Loss**

The loss of productivity associated with the conditions of health considered in this study will examine the productivity of paid work. When estimating the final cost estimate, the iMTA Productivity Value Questionnaire (iPCQ) will be implemented (Bouwmans et al., 2015). In estimating the cost of productivity, absenteeism, presenteeism and paid work will be included. Next, by comparing the missing working days with the average working hours per day, the total number of reduced productive hours due to absenteeism is then determined as shown below:

Absenteeism = Total number of lost productive hours  $\times$  average working hours per day

Nonetheless, the calculation of presenteeism is different and shown as follows. Assume that the respondent X was troubled during the trials by health problems while at work for 10 days. On the ten-point scale, he replied '8.' In other words, he managed to accomplish approximately 80.0% of the job he usually do was managed to be doing even after the treatment. Therefore, lost productivity amounted to 20 percent per day, implying a loss of 10\* 0.2 days= 2 working days or 16 hours. Costs of productivity related to would thus be determined as

Presenteeism = Number of workdays impaired \* [1-(efficiency score/10)] \* number of hours per workday

# 3.4.3 Estimation of the Economic Cost of Cancer Care

The financial costs of cancer care are a burden to cancer-diagnosed patients their families and society as a whole. Generally, the financial costs of cancer are health care costs and non-health care costs. Costs of health care are specified as spending on medical care during diagnosis, recovery, rehabilitation and related medical costs. Direct medical costs are costs that come along with services received by patients such as hospitalization, surgery, physicians visits and treatment costs. In addition, it is measured by insurance payments and patient's out-of-pocket co-payments and deductibles. Other than that, non-health care cost is the cost related to consumption of non-health care services such as travel cost, relocation, supplementation cost, property loss and childcare.

#### 3.5 Research Design

In this study, face-to-face interviews and a quantitative approach is used to measure the burden of illness on cancer patients from economic and psychological perspectives. Intensive and comprehensive questionnaire will be created to fulfil the objectives and cancer survivors will be recruited in the study. This survey will be conducted in Department of Radiotherapy, Oncology and Palliative Care Unit in Sarawak General Hospital. The primary data will be analysed by using Statistical Package the Social Science (SPSS) software.

## **3.5.1 Population and Sample Size**

The population studied was cancer patients that have been undergoing cancer treatment in the past 5 years and who were willing to share past knowledge or experience before and after the sudden impact of cancer. The survey was conducted in the Department of Radiotherapy, Oncology and Palliative Care Unit in Sarawak General Hospital. It serves as the main tertiary hospital in the state of Sarawak. The selected cancers studied in this research are the top 4 common cancers in Sarawak, which are, breast, colorectal, lung and nasopharyngeal cancers (National Cancer Registry, National Cancer Institute & Ministry of Health, 2018; SGH's RTU, 2019).

The study calculated the sample size for the target group using the following method. The standard deviation was set at 0.5 with a margin of error at 5 percent for categorical data and a z-score of 95 percent with a confidence level of 1.96. The top 4 common cancers had a sum total of 5094 cases from 2014 to 2018. The standard formula to compute the sample size is shown below:

$$\frac{[z^2 \times p(q)]/e^2}{1 + [z^2 \times p(q)/e^2 \times N]}$$

where;

z= z-score

p= standard deviation

e= margin of error

N= population size

$$\frac{[1.96^2 \times 0.5(0.5)]/0.5^2}{1 + [1.96^2 \times 0.5(0.5)/0.5e^2 \times 5,094]}$$
  
=357

The proposed sample size is deemed appropriate with a minimum sample size of 357 according to the calculation postulated by Sekaran and Bougie (2010) at 95.0% confidence level. Probability sampling and non-probability sampling was the two standard categories of methods used. In this study, non-probability sampling will be conducted as cancer survivors are the only component to be considered. Purposive sampling is applied to obtain a representative sample of the Sarawak population whereas snowball sampling will be used to find more potential respondents.

## **3.5.2 Research Instrument**

The questionnaire survey form contains a section to determine the demographic profile, the clinical profile, financial burden, societal burden and psychological symptoms, as well as quality of life of the cancer patients. In contrast, the questionnaire is used to collect all the possible information from cancer patients or their families on the diagnosis and financial aspects of the illness, to provide detailed information on the expense and sources of cancer treatment, to monitor patients for a certain duration of follow-up evaluation, to determine how patients finance cancer treatment and to determine how patients minimize any spending on cancer treatment and management. In addition, the loss for terms of employability due to illness is quantified due to illness in the loss of absenteeism and work presenteeism. Finally, the study will consider the quality of life of patients and families. The questionnaire is separated into several sections as shown in the following page.

- I. Demographic profile
- II. Clinical profile
- III. Financial impact
  - a. Direct medical costs
  - b. Direct non-medical costs
  - c. Long-term Follow-up Costs
  - d. Out-of-pocket Expenditure for Additional Drugs
  - e. Financial Toxicity
  - f. Productivity at Work

## 3.5.3 Inclusion and Exclusion Criterion

All adult patients aged 18 years and above with any of the four selected cancers were included on obtaining the informed consent. The exclusion criteria are as follows:

- I. Minor subjects (below 18 years old)
- II. Patients who are deemed vulnerable groups such as prisoners (including those who may be subjected to any type of study coercion), children, patients with concomitant psychiatric illnesses, patients who are feverish or those without the mental capacity (either temporarily or permanently) to fully understand the subject of the study's participant details and purpose.
- III. Patients who are in severe pain and unable to voluntarily cooperate for participation
- IV. Patients who are hemodynamically unstable or require resuscitation

## **3.5.4 Data Collection**

The data collection was completed via a face-to-face interview using the research instrument developed in the present study. To ensure validity and reliability of the data, the research instrument was tested for its face validity and constructs reliability via pilot testing. The cancer survivors suffering from either one of the top four cancer types targeted in the present study were recruited to furnish information needed for the study during their follow-up sessions at the Department of Radiotherapy, Oncology and Palliative Care Unit in the Sarawak General Hospital. To ensure that the study upholds a significant level of ethical protection, the survey was performed on condition of consent from the respondents, in which consent forms needed to be signed before the interview began. Furthermore, any language barrier was solved by

having a translator present during the interview session. Therefore, respondents who were not able to converse fluently in the English or Malay language were able to share their information in comfort. In this way, accuracy of the collected data could be maintained.

### **3.6 Statistical Analysis**

The quantitative data obtained from the face-to-face interview will be evaluate based on the objectives of the study. The Statistical Package for the Social Science (SPSS) will be used for statistical analysis which comprises of frequency analysis, descriptive analysis, normality test, non-parametric test (Kruskal Wallis test and Mann-Whitney test), reliability analysis and logistic regression.

#### **3.6.1 Descriptive Statistical Analysis**

Descriptive statistical analysis sums up data to provide and demonstrate the important features of sample and transforms the raw data into information that the reader can easily comprehend and analyse. The significant findings of results were presented in the form of ranges, quartiles, distribution and standard deviation, which helped to identify the differences between groups.

## **3.6.2 Frequency Analysis**

Frequency analysis is a form of descriptive statistics. Frequency analysis was used to present a summary number of occurrences of each respondent. It helped to reveal the amount of non-responses and missing values as well as outlier and extreme values. By

applying this analysis, readers were able to understand the trend of respondents answers.

#### **3.6.3 Normality Test**

The Kolmogorov-Smirnov statistics belongs to the supremum class of empirical distribution function (EDF) statistics and is based on the largest vertical difference between the hypothesized and empirical distributions (Conover, 1999). The Shapiro and Wilk (1965) test was originally restricted to sample sizes of less than 50. However, it is preferable due to its good power properties and ability to detect departures from normality because of either skewness or kurtosis (Mendes & Pala, 2003; Althouse et al., 1998).

#### 3.6.4 Non-parametric Statistics (Kruskal Wallis Test and Mann-Whitney Test)

The Kruskal-Wallis test is used to compare more than two groups of variables with one-way ANOVA whereas the Mann Whitney Wilcoxon test is used to determine whether two sample means were equal or not with the application of independent sample t-test. Both tests were used when data were not normally distributed.

## **3.6.5 Reliability Analysis**

A reliability test is a way of measuring the stability and reliability of the instruments over time. Rule of thumb states that a Cronbach's Alpha of 0.6 to 0.7 is the minimum acceptable level and 0.9 indicates the best level.

## 3.6.6 Binary Logistic Regression

Binary logistic regression reflects the appropriate regression analysis for a dichotomous (binary) dependent variable. It is a predictive analysis, like all regression analyses that is used to characterize data and explain the correlation between a binary variable and one or more individual nominal, ordinal, interval or ratio-level variables.

# 3.7 Pilot Test

A preliminary study was performed before the final face-to-face interview to determine feasibility, time, cost and to develop the study design with a small sample size. Pilot testing is designed to identify and fix any potential problems prior to the actual survey. In this way, this study was able to include more coherent questionnaires addressing the study's objectives.

#### 3.8 Concluding Remarks

To conclude, this study used surveys to obtain primary data form. In this study, faceto-face interviews were carried out. A quantitative approach was used to measure the burden of illness on cancer patients from an economic perspective. An intensive and comprehensive questionnaire was created to fulfil the objectives. Cancer survivors were recruited in the study. This survey was conducted in Department of Radiotherapy, Oncology and Palliative Care Unit in Sarawak General Hospital. The primary data was analysed using Statistical Package the Social Science (SPSS) software. Both direct and indirect costs were used to capture the economic burden of cancer. Direct costs refer to medical costs and non-medical costs. Other than that, the human capital approach was applied to quantify productivity loss.

# CHAPTER FOUR EMPIRICAL RESULTS AND DISCUSSION

# 4.0 Introduction

The data collection presents along with the findings interpreted and interviewed in the Department of Radiotherapy and Oncology (RTU), Sarawak General Hospital. The respondents studied were known as cancer survivors that received treatment and follow-up within the period of 2010 to 2019 in RTU. Data were tabulated to present demographic profile, financial costs, level of financial toxicity as well as productivity cost of cancer survivors by using Statistic for Social Science (SPSS) version 23.

## 4.1 Demographic Characteristics of Cancer Survivors

## 4.1.1 Distribution of Cancer Survivors by Gender

The demographic profile comprises gender, age, ethnicity, ethnic division, marital status and highest level of education at baseline. A face-to-face interview was carried out on 388 cancer survivors who comprised 142 males (36.6%) and 246 females (63.4%).



Male Female

Figure 4.1: Distribution of Cancer Survivors by Gender

The following figure showed the different types of cancer among both male and female cancer survivors. The female breast cancer survivors proportionated highest at 142 (57.7%) and second top on colorectal cancer at 56 (22.8%). There were 51 (35.9%) and 2 (1.4%) of male cancer survivors on colorectal cancer and breast cancer accordingly.



Figure 4.2: Distribution of Primary Cancer Site by Gender

Both male and female cancer survivors on lung cancer were 38 (26.8%) and 23 (9.3%) respectively. Followed by 51 (35.9%) of male nasopharyngeal cancer survivors and 25 (10.2%) of female nasopharyngeal cancer survivors.

## 4.1.2 Distribution of Cancer Survivors by Age Group

A similar trend of cancer statistics was obtained from Sarawak General Hospital. The highest group of cancer patients were breast cancer, follow by colorectal cancer, lung cancer and nasopharyngeal cancer. The age group below 50 and 50 to 59 years old constituted the largest portion on breast cancer survivors at 45.8% and 36.8% respectively. Moreover, 43.9% of colorectal cancer survivors and 36.1% of lung

cancer survivors were highest at the aged of 60 to 69 years old. From the results, it can be seen that most of breast cancer survivors were in Stage I and Stage II. This showed that an early detection of breast cancer secures higher rates of survival.



**Figure 4.3:** Distribution of Age Group by Types of Cancer

On the other hand, colorectal cancer showed higher of survivor rate in those aged of 60 to 69 years old. Veettil et al. (2016) also proved that the highest proportion of colorectal cases were in patients aged 60-69 years and showed the same pattern in Singapore. Besides this, lung cancer survivors were mostly diagnosed around 60 years. This is equivalent to the outcome of related lung cancer research (Siang et al., 2016).

## 4.1.3 Distribution of Cancer Survivors by Marital Status

A large proportion of 335 (86.3%) married respondents were interviewed in the study. The second largest group of 41 (10.6%) respondents were single. Both divorced and widowed cancer survivors numbered 6 in total (1.5%).



• Single • Married • Divorced • Widowed Figure 4.4: Distribution of Cancer Survivors by Marital Status

# 4.1.4 Distribution of Cancer Survivors by Ethnicity

The greatest survival rate of cancer was achieved by Chinese ethnics at 160 or 41.2% whereas Malay ethnics placed the second at 22.9% (89 respondents). This was followed by the Iban (16.2% or 63 respondents) and the Bidayuh (15.2% or 59 respondents). Among the smallest survival rate of cancer was made up of the Melanau (2.3% or 9 respondents) and the orang Ulu (2.1% or 8 respondents).



Figure 4.5: Distribution of Cancer Survivors by Ethnicity

Based on the National Cancer Registry, National Cancer Registry & Ministry of Health Malaysia (2018), Chinese population has the highest rate of colorectal cancer cases in Malaysia. This was further supported by the findings in this study that comprised 62 Chinese respondents (57.9 percent) among the studied population. Furthermore, the ethnic distribution of survivors of breast cancer is 41% Chinese (59 respondents), 31.9% Malay (46 respondents) and 16.7% Iban (24 respondents).



Figure 4.6: Distribution of Ethnicity by Types of Cancer

Among the 61 lung cancer survivors, those of Chinese ethnicity achieved better survival rates compared to those of Malay ethnicity (24.6% or 15 respondents), the Bidayuh (14.8% or 9 respondents), the Iban (14.8% or 9 respondents) and the orang Ulu (1.6% or 1 respondent). On the other hand, a study carried out by Devi et al. (2004) provided evidence on higher risk of nasopharyngeal cancer among the Bidayuh compared to other ethnicities in Sarawak General Hospital. This result was equivalent to the findings from this study that showed the Bidayuh had the highest survival rate of nasopharyngeal cancer at 36.8%.



## 4.1.5 Distribution of Cancer Survivors by Division of Residence

Figure 4.7: Distribution of Cancer Survivors by Ethnic Division

The three divisions with the largest number of cancer survivors were Kuching (56.7% or 220 respondents), Serian (9.3% or 36 respondents) and Sibu (7.5% or 29 respondents). This is followed by Miri (5.4% or 21 respondents), Samarahan (5.2% or 20 respondents), Sri Aman (4.4% or 17 respondents), Bintulu (3.9% or 15 respondents), Sarikei (3.4% 13 respondents) and Betong (2.6% or 10 respondents). The divisions with the smallest number of cancer survivors were Mukah (0.8% or 3 respondents), Limbang (0.8% or 3 respondents) and Kapit (0.3% or 1 respondent).

## 4.1.6 Distribution of Cancer Survivors by Education Level

Out of 388 cancer survivors, the highest education level of most was upper secondary schooling (30.4% or 118 respondents), lower secondary schooling (21.9% or 85

respondents), primary schooling (21.6% or 51 respondents) and no formal schooling (13.1% or 51 respondents).



Figure 4.8: Distribution of Cancer Survivors by Education Level

This was followed by 5.2% or 20 respondents and 5.4% or 21 respondents that received diploma and bachelor's degree respectively. The smallest proportion of cancer survivors had received a master's degree (1.3% or 5 respondents) and certificate (1.0% or 4 respondents).

Demographic	Categories	Frequency	Percentage
Variables		(N=388)	(%)
Gender	Male	142	36.6
	Female	246	63.4
Ethnicity	Malay	89	22.9
	Chinese	160	41.2
	Bidayuh	59	15.2
	Iban	63	16.2
	Melanau	9	2.3
	Ulu	8	2.1
Age Group	Less than 50	123	31.7
	50-59	110	28.4
	60-69	108	27.8
	70 and above	47	12.1
Marital Status	Single	41	10.6
	Married	335	86.3
	Divorced	6	1.5
	Widowed	6	1.5
Area of Residence	Kuching	220	56.7
	Samarahan	20	5.2
	Serian	36	9.3
	Sri Aman	17	4.4
	Betong	10	2.6
	Sarikei	13	3.4
	Sibu	29	7.5
	Mukah	3	0.8
	Bintulu	15	3.9
	Kapit	1	0.3
	Miri	21	5.4
	Limbang	3	0.8
Education Level	No formal Schooling	51	13.1
	Primary Schooling	84	21.6
	Lower Secondary	85	21.9
	Schooling	00	-1.7
	Upper Secondary	118	30.4
	Schooling	110	2011
	Diploma	20	5.2
	Bachelor's Degree	21	5.4
	Master's Degree	5	1.3
	Certificate	4	1.0
Treatment Pathway	Public Hospital	308	79.4
outmont i univay	Public and Private	80	20.6
	Hospitals	00	20.0

|--|
#### 4.2 Clinical Profile of Cancer Survivors

#### 4.2.1 Distribution of Cancer Survivors by Primary Cancer Site

This study comprised 144 breast cancer survivors (37.1%), 107 colorectal cancer survivors (27.6%), 61 lung cancer survivors (15.7%) and 76 nasopharyngeal cancer survivors (19.6%). A total of 388 respondents were engaged during the recruitment period compared to the minimum required sample size which was 357.



Figure 4.9: Distribution of Cancer Survivors by Cancer Site

#### 4.2.2 Distribution of Primary Cancer Site based on Stages of Cancer

Most of the breast cancer survivors were diagnosed in the early stages, that is Stage I (25.0%) and Stage II (38.2%). Breast cancer survivors who were diagnosed in the late stages (Stage III and Stage IV) constitute 20.1% and 16.7% respectively. In Malaysia, most cases of lung cancer were either diagnosed when locally advanced or with distant metastasis at the late stage. There was a significant delay of treatment due to failure of detection and beliefs in traditional complementary medicine (Loh et al., 2006). This was similar with the outcomes tabulated in Figure 4.10 as the majority of lung cancer survivors were diagnosed during Stage IV at 62.3 percent. Furthermore, 90.0% of lung

cancer cases in Malaysia were diagnosed in the late stage with poor curative treatment (Lung Cancer Network Malaysia [LCNM], 2019).



Nasopharyngeal Lung Colorectal Breast
 Figure 4.10: Distribution of Cancer Survivors by Cancer Site

Most survivors of colorectal cancer were diagnosed at Stage III at 43.9 percent. This finding was similar with the study carried out by Veettil et al (2016) and could be attributed to late detection. Public understanding of the growing prevalence of colorectal cancer and screening participation rates are small in Malaysia. From the results, cancer survivors with colorectal cancer, lung cancer and nasopharyngeal cancer were mostly diagnosed at late stages (Stage III and Stage IV) whereas breast cancer survivors in general constituted more than half the number in each stage. According to Murallithran et al. (2018), cancers are typically identified or treated late in Malaysia with dramatic consequences in terms of their late detection on survival. Hence, efforts to control cancer are urgently needed.

Disease	Categories	Frequency	Percentage
Characteristics		(N=388)	(%)
Primary Cancer	Breast	144	37.1
Site	Colorectal	107	27.6
	Lung	61	15.7
	Nasopharyngeal	76	19.6
Primary Site	Breast (Stage I)	36	25.0
and Cancer	Breast (Stage II)	55	38.2
Stages	Breast (Stage III)	29	20.1
	Breast (Stage IV)	24	16.7
	Colorectal (Stage I)	15	14.0
	Colorectal (Stage II)	31	29.0
	Colorectal (Stage III)	47	43.9
	Colorectal (Stage IV)	14	13.1
	Lung (Stage I)	12	19.7
	Lung (Stage II)	2	3.3
	Lung (Stage III)	9	14.8
	Lung (Stage IV)	38	62.3
	Nasopharyngeal (Stage I)	17	22.4
	Nasopharyngeal (Stage II)	16	21.1
	Nasopharyngeal (Stage III)	18	23.7
	Nasopharyngeal (Stage IV)	25	32.9

Table 4.2: Summary of Disease Characteristics of Cancer Patients

#### 4.3 Normality Test Results

The Kruskal-Wallis test was used to compare more than two groups of variables with one-way ANOVA whereas the Mann Whitney Wilcoxon test was used to determine whether or not the two sample means were equal with application of the independent sample t-test. Both tests were used as studied variables were not normally distributed. Based on the normality tests on both Shapiro-Wilk and Kolmogorov-Smirnov test, the results showed statistical significance at a 5 percent level of significance. Thus, the null hypothesis was rejected. This indicates that all the variables in the table below are not normally distributed.

Variables	Kolmogorov	-Smirnov	Shapiro-Wilk			
variables	Statistic	<i>p</i> -value	Statistic	<i>p</i> -value		
Financial Toxicity Score	0.083	0.000*	0.977	0.000*		
Total Core Treatment Costs	0.366	0.000*	0.347	0.000*		
Total Follow-up Costs	0.403	0.000*	0.227	0.000*		
Total Non-medical Costs	0.309	0.000*	0.440	0.000*		
Total Financial Costs	0.308	0.000*	0.471	0.000*		

 Table 4.3: Normality Tests Results

Note: Asterisk (\*) denotes 5% level of significance.

#### 4.4 Reliability Analysis Results

The reliability test is a way of measuring the stability and reliability of the instruments over time. Rule of thumb states that Cronbach's Alpha of 0.6 to 0.7 is the minimum acceptable level and 0.9 is the best level. Based on the results of reliability analysis for this study, the financial toxicity score is 0.910 of Cronbach's Alpha with 11 items, which corresponds to the best level.

#### 4.5 Financial Costs of Cancer Care (Overall)

The overall spending on cancer treatment is categorized into core treatment costs, follow-up costs and non-medical costs. The core treatment costs include treatment such as chemotherapy, radiotherapy and surgery. Expenditures on prevention, diagnosis, long-term surveillance, recovery and palliative care are grouped under follow-up costs. Non-medical costs include travel expenses, educational materials, over-the-counter medicine, domestic assistance and childcare. Figure 4.11 shows the breakdown of cancer costs and overall financial costs of cancer.



Figure 4.11: Total Financial Costs of Cancer Care

Based on Figure 4.11, all groups of cancer survivors tend to spend more on nonmedical costs especially colorectal cancer survivors. It can thus be concluded that the use of stoma, ostomy beg for lifetime imposes an extra financial burden on their families. There were statistically significant differences between the Chinese compared to both Malays and Sarawak indigenous groups on spending on core treatment costs for breast cancer, colorectal cancer and nasopharyngeal cancer. The findings indicated that the Chinese spent more on cancer care. This enabled the Chinese particularly from mid and high-income families to obtain care in both public and private hospitals. A better financial ability gave the Chinese cancer survivors better access to healthcare and benefits as well as higher rates of income.

Besides this, there was a statistically significant difference in core treatment and non-medical costs among the three ethnicities for nasopharyngeal cancer and lung cancer. The Sarawak Indigenous groups with colorectal cancer tended to spend more on non-medical costs whereas the Chinese spent more on core treatment for breast cancer. The Malays who were survivors of nasopharyngeal cancer spent more on nonmedical costs. There were statistically significant differences in the follow-up costs of survivors of colorectal cancer, lung cancer and nasopharyngeal cancer. In addition, cancer survivors who received college or university education were first for overall spending on breast cancer compared to cancer survivors who received primary or secondary education or no formal schooling.

There were statistically significant differences found in the cost of cancer care between households of different incomes. Breast cancer late stage survivors from the high-income household (T20) group showed relatively higher spending in core treatment, follow-up costs and non-medical costs. Follow-up costs of colorectal cancer were significantly different between between low and high-income groups in Stage I and Stage II. Breast cancer survivors spent most for core treatment during Stage III (RM3,692.00) whereas colorectal cancer survivors spent most on core treatment and follow-up during Stage II at RM5,150.00 and RM1,490.00 respectively as shown in Table 4.4. Higher financial spending at RM14,150.60 was noted for breast cancer survivors with a family history. The total financial costs for breast cancer survivors were relatively high during Stage III at RM13,080.00 and Stage II for colorectal cancer at RM18,798.00.

Table 4.4 shows that spending for chemotherapy burdens in terms of core treatment (breast, lung and nasopharyngeal) cancer survivors. Besides, radiotherapy showed a statistically significant difference for core treatment spent on breast cancer and follow-up costs spent on lung cancer. Further expenditure for surgery treatment among breast cancer and colorectal cancer were also significant at 5 percent. A statistically significant core treatment, follow-up costs, and total financial costs among all four cancer groups impose a higher rate with treatment received at both public and private hospitals. On the other hand, the overall financial costs indicated a significant gap in chemotherapy between lung and nasopharyngeal cancer, followed by breast and colorectal cancer on surgery as shown in Table 4.5.

	Financial Costs Per Person by Cancer Types													
						Me	edian (IQR)							
			Breast			Colorectal			Lung		N	asopharyngea	ત્રી	
		СТС	FC	NC	СТС	FC	NC	СТС	FC	NC	СТС	FC	NC	
						]	Ethnicity							
Malay	У	768.00	1,130.00	1,412.50	834.00	477.50	1,902.50	225.00	1,450.00	1,200.00	726.00	92.50	2,660.00	
		(556.00)	(2,464.25)	(2,092.50)	(664.75)	(1,179.25)	(8,165.75)	(342.00)	(3,480.00)	(2,236.20)	(750.25)	(156.25)	(3,265.05)	
Chine	ese	11,135.00	1,425.00	4,086.90	1845.50	1,197.00	5,539.00	536.00	2,225.00	2,580.00	2,061.50	635.00	8,447.50	
		(17,032.00)	(3,360.00)	(11,184.00)	(14,357.00)	(5,187.75)	(8,706.25)	(960.50)	(6,190.00)	(7,250.00)	(22,037.00)	(1,577.50)	(14,368.50)	
Saraw	wak	768.00	750.00	2,800.00	874.00	215.00	3,880.00	423.00	250.00	1,430.00	811.00	150.00	2,636.25	
Indige	enous	(1,542.00)	(2,000.00)	(5,240.00)	(1,532.00)	(1,449.00)	(6,465.76)	(695.50)	(4,145.00)	(1,364.00)	(533.00)	(287.50)	(3,017.05)	
group	)													
Krusk	kal Wallis	0.000*	0.361	0.000*	0.001*	0.014*	0.044*	0.210	0.037*	0.052	0.001*	0.011*	0.010*	
(p-val	lue)													
							Age							
Less t	than 50	1,248.00	1,395.50	2,835.00	1,122.00	600.00	5,136.00	1,749.00	550.00	1,430.00	950.00	180.00	3,106.50	
		(12,369.50)	(2,696.25)	(7,188.75)	(1,362.00)	(5,097.50)	(8,813.50)	(64,211.25)	(42,480.00)	(2,900.00)	(686.00)	(537.50)	(5,450.50)	
50-59	)	1,150.00	975.00	2,160.00	1,424.00	285.00	5,998.40	810.00	1,250.00	1,080.00	946.00	200.00	4,244.10	
		(8,377.00)	(2,010.00)	(5,513.00)	(8,188.00)	(4,775.00)	(7,985.00)	(801.00)	(2,025.00)	(3,080.00)	(1,133.00)	(300.00)	(4,090.00)	
60-69	)	768.00	1,450.00	1,822.50	1,184.00	575.00	4,770.00	371.00	1,567.50	2,211.10	1,092.00	150.00	3,803.00	
		(7,981.00)	(4,960.00)	(5,487.50)	(6,093.98)	(2,790.00)	(7,972.50)	(648.00)	(3,831.25)	(6,073.10)	(1,165.00)	(357.50)	(4,641.30)	
70 an	id above	824.00	700.00	1,050.00	1,156.00	585.00	5460.00	318.00	4,025.00	1,800.00	608.00	150.00	2,140.00	
		-	-	-	(6,008.52)	(2,636.00)	(8,191.25)	(349.00)	(15,917.50)	(2,502.00)	(224.00)	(325.00)	(3,775.00)	
Krusk	kal Wallis	0.290	0.993	0.642	0.818	0.969	0.816	0.233	0.211	0.688	0.142	0.984	0.518	
(p-val	lue)													
						Edu	cation Level							
No fo	ormal	824.00	700.00	1,450.00	866.00	207.50	2,670.00	318.00	900.00	1,240.00	732.00	157.50	3,916.00	
Schoo	oling	(825.00)	(2,512.50)	(3,031.00)	(1,762.25)	(312.50)	(5,471.44)	(215.00)	(6,088.75)	(1,740.00)	(461.50)	(256.25)	(6,070.00)	
Prima	ary	761.00	465.00	1,660.00	1,153.00	885.00	5,215.00	610.00	1,580.00	1,902.10	973.00	175.00	3,917.00	
Educa	ation	(625.50)	(1,499.50)	(2,511.75)	(3,519.25)	(3,138.75)	(6,796.63)	(869.25)	(3,956.25)	(4,647.50)	(1,472.00)	(490.00)	(4,160.78)	
Secor	ndary	1,016.00	1,100.00	2,600.00	1,510.00	600.00	5,480.00	371.00	1,755.00	1,956.00	950.00	150.00	2,761.25	
Educa	ation	(9,123.50)	(2,110.00)	(6,030.00)	(10,575.00)	(4,735.00)	(9,325.00)	(600.00)	(4,506.00)	(4,341.40)	(514.50)	(312.50)	(3,875.63)	
Colle	ege/	10,934.00	2,037.50	5,645.08	1,124.00	2,529.50	2,596.50	3,074.00	630.00	1,202.50	1,326.50	1,247.50	4,099.85	
Unive	ersity	(16,317.50)	(7,128.00)	(18,228.11)	(1,311.50)	(5,847.75)	(6,784.00)	-	(12,216.25)	(13,373.75)	(36,144.50)	(4,666.25)	(10,758.00)	
Educa	ation													

**Table 4.4:** Results of Association between Financial Costs Per Person by Cancer Types, Sociodemographic and Clinical Profile

	Financial Costs Per Person by Cancer Types												
					Me	dian (IQR)							
	and	Breast		ora	Colorectal		CTC	Lung		Na	asopharyngea		
		FC	<u>NC</u>		FC			FC			FC		
Kruskal Wallis	0.000*	0.003*	0.030*	0.176	0.028*	0.326	0.558	0.905	0.405	0.509	0.515	0.870	
(p-value)					<b>T</b> 1								
Working	1 726 00	1 264 50	2 622 00	1 527 50	1 220 50	oyment Status	297.50	6 860 00	1 400 00	050.00	175.00	2 260 00	
working	(1281250)	(2.831.25)	(5.021.25)	(15,787,00)	(5,531,25)	(7,077,50)	(9.718.00)	(33,640,01)	(0.506.00)	(582.00)	(380.00)	(2,200.00)	
Unamployed	768.00	1 032 50	(3,021.23)	1 1 22 00	215.00	(7,077.30)	(9,718.00)	1 825 00	(9,390.99)	1.074.00	100.00	(2,334.48)	
Onempioyed	(10.896.00)	(2, 167, 50)	(6,906,30)	(27,066,00)	(1.082.50)	(7,005,25)	(460.00)	(3,680,00)	(3,600,00)	(525.00)	(1.012.00)	(656500)	
Retired	1 030 00	1 575 00	2 600 00	1 126 00	592 50	4 715 50	(400.00)	1 390 00	1 800 00	770 50	237 50	3 199 20	
Retired	(8,007,00)	(5.490.00)	(7,070,00)	(.3391.02)	(1.924.50)	(6,973,60)	(1.464.00)	(382375)	$(4\ 480\ 95)$	(1.330.75)	(335.00)	(4.108.30)	
Others	1.090.00	825.00	1.750.00	1.148.50	707.50	5.205.00	371.00	1.045.00	1.690.00	798.00	125.00	3.526.50	
	(5.808.50)	(2,025.00)	(7.395.00)	(2,739.75)	(5.112.50)	(9.675.00)	(618.00)	(3.031.25)	(4.293.00)	(1,446.25)	(247.50)	(4,907.50)	
Kruskal Wallis	0.128	0.658	0.982	0.744	0.393	0.775	0.398	0.087	0.976	0.857	0.601	0.204	
(p-value)													
					Baseline I	<b>Household Inc</b>	come						
Low Income	858.00	850.00	2,330.00	1,098.00	355.00	5,136.00	362.00	1,300.00	1,452.50	922.00	150.00	3,185.00	
Household	(3,192.00)	(1,775.00)	(4,875.00)	(4,576.00)	(1,675.00)	(5,680.00)	(374.00)	(3,388.74)	(1,998.00)	(632.75)	(282.50)	(3,508.73)	
(B40)													
Median Income	1,023.00	779.50	2,215.00	1,480.00	727.50	4,089.50	605.50	2,470.00	3,506.60	774.00	250.00	2,000.00	
Household	(5,864.00)	(2,105.00)	(4,223.75)	(6,823.50)	(3,548.75)	(8,625.00)	(3,483.25)	(23,510.00)	(17,322.75)	(1,306.50)	(640.00)	(7,795.60)	
(M40)	12 (00.00	2 200 00	7 500 00	11 462 00	2 0 2 7 0 0	0.120.00	1 502 00	1 220 00	2240.00	5 42 00	275.00		
High Income	13,680.00	3,300.00	7,500.00	11,462.00	2,937.00	9,120.00	1,702.00	4,220.00	2240.00	543.00	375.00	5,500.00	
Household	(18,426.00)	(9,575.00)	(17,315.00)	(29,581.50)	(5,656.25)	(17,882.57)	(57,305.00)	(22,680.00)	(22,227.50)	-	-	-	
(120) Krashal Wallia	0.000*	0.000*	0.000*	0.049*	0.000*	0.206	0.146	0.095	0.292	0.704	0.166	0.102	
$(n_{v})$	0.000*	0.000*	0.009*	0.048*	0.022*	0.390	0.140	0.085	0.282	0.794	0.100	0.192	
(p-value)					Area	of Residence							
Capital City-	1.016.00	1.324.50	1.737.80	1.224.00	520.00	3.000.00	375.00	2087.50	1.143.00	950.00	200.00	2.108.00	
Kuching	(12,447.50)	(2.847.50)	(2.888.50)	(5,993,98)	(2.225.00)	(7.125.00)	(528.00)	(6.629.25)	(1.983.74)	(1.003.00)	(315.00)	(3,603.75)	
Outside Capital	1,090.00	922.50	5,211.00	1,105.50	582.50	6,189.20	423.00	1,450.00	2,980.00	822.00	150.00	3,850.00	
City of	(9,037.00)	(1,978.75)	(8,041.00)	(5,559.50)	(4,972.50)	(6,375.00)	(1,594.00)	(2,125.00)	(6,906.00)	(584.00)	(365.00)	(4,320.00)	
Kuching										. ,	. /		
Mann-Whitney	0.901	0.845	0.000*	0.513	0.513	0.003*	0.669	0.108	0.004*	0.387	0.589	0.218	
(p-value)													

Financial Costs Per Person by Cancer Types												
					Me	edian (IQR)						-
	070	Breast		ana	Colorectal		ana	Lung		Na	asopharyngea	<u>al</u>
	СТС	FC	NC	CIC	<u> </u>	<u> </u>	CIC	FC	NC	СТС	FC	NC
Ctore I	1 004 00	1 570 00	1 012 00	959.00		ncer Stages	424.00	2 705 00	2 170 00	714.00	100.00	2 414 40
Stage I	1,004.00	1,570.00	1,912.80	858.00	165.00	5,130.00	424.00	2,705.00	2,170.00	/14.00	180.00	2,414.40
Store II	(1,0031.30)	(2,912.50)	(5,130.00)	(6/2.00)	(355.00)	(8,191.00)	(340.00)	(4,785.00)	(2,440.00)	(523.00)	(225.00)	(2,009.85)
Stage II	(12,006,00)	(2.855.00)	2,764.00	(1451800)	1,490.00	(0.340.00)	408.00	5,187.50	1,529.00	(162.50)	502.50	4,054.55
Stage III	3 602 00	(2,855.00)	(7,195.00)	1 1 22 00	(4,300.00)	5 055 00	565.00	1 550 00	1 086 00	(403.30)	(711.23)	2 030 00
Stage III	(1136800)	(3,705,00)	(7,436,70)	(3.704.00)	(5.015.00)	(6.020.00)	(2838.00)	(30, 110, 50)	(4, 174, 40)	(947.00)	(801.25)	(3,216,18)
Stage IV	663.00	1 097 50	2 455 00	1 237 00	797 50	3 649 75	330.00	1 415 00	1 680 00	1.092.00	100.00	3 500 00
Stage IV	(650,50)	(1.695.50)	(2, 877, 50)	(253877)	(3 892 50)	(9,955,50)	(864.00)	(285125)	(4 846 50)	(1.492.00)	(320.00)	(8,232,51)
Kruskal Wallis	0.002*	0 407	0 312	0.011*	0.026*	0 166	0.922	0 664	0 765	0 324	0 164	0 345
( <i>p</i> -value)	0.002	0.107	0.512	0.011	0.020	0.100	0.722	0.001	0.705	0.521	0.101	0.015
(p (ulue)					Trea	tment Status						
Ongoing	1,030.00	375.00	2,764.00	1,130.00	221.00	4,770.00	507.00	871.50	1,969.50	822.00	150.00	3,120.00
Treatment	(9,920.00)	(2,512.50)	(5,938.00)	(3,084.00)	(1,900.00)	(8,202.50)	(712.00)	(3,802.50)	(2,221.00)	(699.00)	(335.00)	(3,721.00)
Completed	1,090.00	1,650.00	2,360.00	1,237.00	1,197.00	5,337.75	243.50	1,825.00	1,500.00	1,915.00	300.00	4,029.00
Treatment	(9,776.00)	(2,610.00)	(6,720.00)	(15,609.25)	(3,853.75)	(8,048.55)	(396.25)	(6,550.00)	(6,616.90)	(15,338.00)	(557.50)	(9,030.50)
Mann-Whitney	0.970	0.000*	0.514	0.813	0.010*	0.952	0.011*	0.024*	0.618	0.179	0.984	0.514
(p-value)												
					Far	nily History						
Yes	1,106.00	1,842.50	3,801.00	1,230.50	1,487.50	4,715.50	318.00	1,720.00	1,771.50	870.50	250.00	3,552.00
	(12,758.25)	(5,007.50)	(13,252.25)	(9,043.49)	(4,016.25)	(10,986.50)	(505.00)	(4,207.50)	(4,183.75)	(1,280.50)	(613.75)	(9,357.75)
No	1,035.00	970.50	2,122.50	1,184.00	430.00	5,136.00	423.00	1,475.00	1,800.00	897.50	150.00	3,178.25
N	(8,240.00)	(1,933.75)	(4,221.50)	(5,870.00)	(2,855.00)	(7,581.50)	(767.25)	(4,225.00)	(3,698.00)	(672.00)	(273.75)	(3,527.48)
Mann-Whitney	0.542	0.425	0.006*	0.896	0.896	0.951	0.408	0.8/1	0.687	0.987	0.599	0.639
(p-value)					Treat	mont Dothwo	7					
Public Hospital	754.00	800.00	1 725 60	945.00	445.00	4 902 50	373.00	1 512 50	1 530 00	822.00	150.00	3 120 00
i ublic Hospital	(555.00)	$(1\ 810\ 00)$	(2.912.50)	(926.25)	(281125)	(7,368,25)	(487.00)	(4.033.75)	(2,860,00)	(655.50)	(312.50)	(3,661,50)
	(555.00)	(1,010.00)	(2,)12.30)	()20.25)	(2,011.23)	(7,500.25)		(4,055.75)	(2,000.00)	(055.50)	(312.50)	(3,001.50)
Public and	13,680.00	1,75.00	/,500.00	20,918.00	1,075.00	5,435.50	/5,810.00	61,425.00	12,645.00	101,000.0	2,085.00	7,180.00
Private	(9,547.00)	(4,/15.00)	(12,8/1.50)	(24,704.00)	(0,002.50)	(8,602.50)	-	-	-	0	-	-
Monn Whitney	0.000*	0.000*	0.000*	0.000*	0.000*	0.286	0.000*	0.126	0.030*	-	0.027*	0.459
$(n_{\rm value})$	0.000*	0.000*	0.000*	0.000*	0.000*	0.280	0.000*	0.150	0.039*	0.000**	0.027*	0.438
(p-value)												

Financial Costs Per Person by Cancer Types												
					Me	dian (IQR)						
		Breast			Colorectal			Lung		Na	sopharynge	al
	СТС	FC	NC	СТС	FC	NC	СТС	FC	NC	СТС	FC	NC
~ .					Che	emotherapy						
(Yes)	1,160.00 (10,899.50)	980.00 (2,070.00)	2,820.00 (7,158.75)	1,184.00 (3,317.50)	520.00 (3,392.50)	4,770.00 (7,888.00)	569.50 (2,391.25)	1,440.00 (4,150.00)	2,269.60 (7,828.25)	950.00 (860.00)	165.00 (395.00)	3,500.00 (4,091.55)
Chemotherapy (No)	484.50 (10,024.00)	1,667.50 (3,611.25)	1,730.00 (2,783.79)	1,100.00 (15,826.00)	715.00 (3,811.25)	5,457.75 (7,612.75)	150.00 (127.50)	1,755.00 (4,337.50)	1,200.00 (1,897.50)	420.00 (84.00)	150.00 (200.00)	2,140.00 (2,454.00)
Mann-Whitney ( <i>p</i> -value)	0.002*	0.121	0.029*	0.410	0.262	0.753	0.000*	0.593	0.015*	0.000*	0.378	0.389
					Ra	diotherapy						
Radiotherapy (Yes)	1,182.00 (10,926.00)	975.00 (2,655.00)	2,475.00 (7,633.40)	1,187.00 (7,671.50)	320.00 (3,923.75)	5,635.00 (8,037.00)	424.00 (720.00)	420.00 (1,450.00)	1,820.00 (3,764.00)	922.00 (637.50)	190.00 (323.75)	3,826.50 (3,970.00)
Radiotherapy (No)	700.00 (5,892.00)	1,430.00 (2,857.50)	2,500.00 (5,450.00)	113.00 (5,191.00)	615.00 (2,800.00)	4,750.00 (7,825.00)	366.50 (500.00)	3,205.00 (8,242.75)	1,680.00 (3,749.75)	718.00 (1,140.00)	100.00 (611.25)	1,496.55 (2,993.75)
Mann-Whitney ( <i>p</i> -value)	0.010*	0.433	0.317	0.485	0.338	0.341	0.726	0.001*	0.372	0.489	0.348	0.020*
						Surgery						
Surgery (Yes)	1,182.00 (11,233.50)	1,319.00 (2,842.50)	2,510.00 (6,580.00)	1,322.50 (7,794.50)	585.00 (3,837.50)	5,187.00 (7,806.25)	452.00 (2,541.75)	1,687.50 (4,691.25)	1,991.50 (4,781.60)	1,480.00 (947.00)	250.00 (450.00)	4,029.00 (13,714.50)
Surgery (No)	468.00 (678.00)	525.00 (1,760.00)	2,474.00 (4,250.00)	618.00 (577.00)	285.00 (1,284.00)	4,020.00 (8,787.50)	330.00 (588.00)	1,450.00 (3,750.00)	1,500.00 (3,787.00)	800.00 (591.00)	150.00 (330.00)	3,120.00 (3,742.05)
Mann-Whitney ( <i>p</i> -value)	0.000*	0.390	0.386	0.018*	0.093	0.349	0.155	0.842	0.396	0.153	0.455	0.686

Pairwise Comparisons												
					Test Stati	stics (Adj. Sig	g)					
		Breast			Colorectal			Lung		Nas	sopharyngeal	l
	CTC	FC	NC	CTC	FC	NC	CTC	FC	NC	CTC	FC	NC
					E	thnicity						
Malay-Sarawak	-4.382	-	-22.775*	-2.415	5.381	-7.455	-	7.309	-	-4.884	-6.560	-0.794
Indigenous	(1.000)		(0.036)	(1.000)	(1.000)	(1.000)		(0.700)		(1.000)	(0.976)	(1.000)
group												
Malay-Chinese	45.040*	-	32.990*	25.173*	13.724	19.632	-	6.348	-	30.089*	24.917*	21.798*
	(0.000)		(0.000)	(0.018)	(0.405)	(0.098)		(0.800)		(0.002)	(0.012)	(0.036)
Sarawak	40.658*	-	10.215	22.758*	19.105*	12.177	-	13.657*	-	25.205*	18.357*	21.003*
Indigenous	(0.000)		(0.706)	(0.003)	(0.015)	(0.223)		(0.031)		(0.001)	(0.029)	(0.009)
group-Chinese												
					Educ	ation Level						
No formal	-1.886	5.860	-3.385	-20.411	-	-	-	-	-	-	-	-
Schooling-	(1.000)	(1.000)	(1.000)	(0.303)								
Primary												
Education												
No formal	-19.903	-10.712	-14.600	-24.573*	-	-	-	-	-	-	-	-
Schooling-	(0.640)	(1.000)	(1.000)	(0.045)								
Secondary												
Education												
No formal	-44.567*	-34.797	-32.918	-36.098	-	-	-	-	-	-	-	-
Schooling-	(0.007)	(0.072)	(0.105)	(0.052)								
College /												
University												
Education	10.016	16 570	11.015	4.1.00								
Primary	-18.016	-16.572	-11.215	-4.162	-	-	-	-	-	-	-	-
Education-	(0.420)	(0.596)	(1.000)	(1.000)								
Secondary												
Education	10 (00*	10 650*	20 522	15 (00								
Education	-42.680*	-40.058*	-29.555	-15.088	-	-	-	-	-	-	-	-
Education-	(0.001)	(0.003)	(0.070)	(1.000)								
College /												
University												
Education												

Pairwise Comparisons													
					Test Stati	stics (Adj. Sig	g)						
		Breast			Colorectal			Lung		Nas	opharyngeal		
	СТС	FC	NC	СТС	СТС	FC	NC	CTC	CTC	FC	NC	СТС	
Secondary	-24.664*	-24.086*	-18.318	-11.526	-	-	-	-	-	-	-	-	
Education-	(0.032)	(0.042)	(0.243)	(1.000)									
College /													
University													
Education													
					Baseline H	ousehold Inco	me						
Low-Income	-4.999	0.301	3.376	-10.222	-11.651	-	-	-	-	-	-	-	
Household-	(1.000)	(1.000)	(1.000)	(0.441)	(0.295)								
Middle-Income													
Household	07.5404	<b>27</b> 000 t		10.001	<b>22 1 5 0 1</b>								
Low-Income	-37.543*	-37.000*	-26.245*	-19.901	-22.178*	-	-	-	-	-	-	-	
Household-	(0.000)	(0.000)	(0.013)	(0.066)	(0.032)								
High-Income													
Household	22 5 42*	27 202*	20 (21*	0.670	10 527								
Middle-Income	-32.343*	$-37.302^{*}$	-29.621*	-9.0/9	-10.527	-	-	-	-	-	-	-	
Household-	(0.007)	(0.002)	(0.020)	(0.939)	(0.857)								
Household													
Tiousciloid					Can	cor Stagos							
Stage IV-	18 674	_	-	-20.031	-17 636	-	-	-	-	_	_	_	
Stage I	(0.510)			(0.494)	(0.757)								
Stage IV-	32,036*	-	_	12.084	11 722	_	-	-	_	_	_	-	
Stage II	(0.009)			(1.000)	(1.000)								
Stage IV-	40.558*	-	-	-1.496	-1.046	-	-	-	-	-	-	-	
Stage III	(0.003)			(1.000)	(1.000)								
Stage I-	-13.362	-	-	-32.115*	-29.358*	-	-	-	-	-	-	-	
Stage II	(0.778)			(0.006)	(0.016)								
Stage I-	-21.884	-	-	-18.535	-16.589	-	-	-	-	-	-	-	
Stage III	(0.220)			(0.264)	(0.428)								
Stage II-	-8.522	-	-	13.580	12.769	-	-	-	-	-	-	-	
Stage III	(1.000)			(0.351)	(0.452)								

Notes: Asterisks (\*) and (\*\*) denote 5% and 10% level of significance, respectively. Abbreviations: CTC, Core Treatment Costs; FC, Follow-up Costs; NC, Non-medical Costs; IQR, Interquartile Range.

				Total Financial	Costs Per Person				
	1	Median (IQR)				Pairwi	ise Comparisons		
	Breast	Colorectal	Lung	Nasopharyngeal		Breast	Colorectal	Lung	Nasopharyngeal
				Eth	nicity				
Malay	3,772.00	3,674.50	3,280.00	4,336.50	Malay-Sarawak	-15.069	-8.191	-	0.680
	(4,697.54)	(9,884.50)	(10,114.20)	(4,762.70)	Indigenous group	(0.291)	(1.000)		(1.000)
Chinese	22,222.00	15,772.50	6,708.00	16,586.00	Malay-Chinese	46.281*	31.530*	-	28.167*
	(21,856.00)	(28,381.00)	(29,450.40)	(25,952.25)		(0.000)	(0.002)		(0.004)
Sarawak	5,143.50	6,640.00	2,830.00	4,264.50	Sarawak Indigenous	31.212*	23.339*	-	28.847*
Indigenous group	(9,806.00)	(10,314.00)	(6,093.00)	(3,638.63)	group-Chinese	(0.001)	(0.002)		(0.000)
Kruskal Wallis	0.000*	0.000*	0.054	0.000*	-	-	-	-	-
( <i>p</i> -value)									
				Age	Group				
Less than 50	8,098.00	10,339.00	4,160.00	4,369.00	Less than 50-50-59	-	-	-	-
	(20,764.00)	(10,699.50)	(88,669.00)	(9,390.00)					
50-59	6,378.00	11,348.00	2,835.00	6,170.00	Less than 50-60-69	-	-	-	-
	(14,392.98)	(24,006.50)	(11,355.00)	(14,450.00)					
60-69	5,321.50	11,664.00	4,973.00	4,491.00	Less than 50-70 and	-	-	-	-
	(16,006.75)	(27,099.10)	(9,306.15)	(5,454.25)	above				
70 and above	5,269.00	11,663.00	6,549.98	4,400.00	50-59-60-69	-	-	-	-
	-	(18,303.19)	(21,158.00)	(3,667.00)					
Kruskal Wallis	0.606	0.756	0.519	0.239	50-59-70 and above	-	-	-	-
( <i>p</i> -value)									
					60-69-70 and above	-	-	-	-
				Educat	ion Level				
No formal	3,515.00	4,580.00	4,645.00	4,950.55	No formal	-7.210	-18.851	-	-
Schooling	(4,578.00)	(6,646.26)	(8,124.25)	(6,443.50)	Schooling-Primary	(1.000)	(0.425)		
					Education				
Primary Education	3,824.50	9,560.50	6,035.50	4,809.50	No formal	-23.340	-28.651*	-	-
	(5,095.25)	(18,713.75)	(17,349.00)	(5,147.90)	Schooling-	(0.369)	(0.011)		
					Secondary Education				
Secondary	6,807.00	12,660.00	4,815.00	4,158.25	No formal	-54.913*	-21.143	-	-
Education	(14,753.00)	(25,842.00)	(27,540.00)	(5,437.13)	Schooling-College /	(0.000)	(0.745)		
					University Education				
College/	25,640.50	12,483.50	2,327.50	9,595.50	Primary Education-	-16.130	-9.800	-	-
University	(32,683.31)	(17,326.75)	(81,701.00)	(60,023.23)	Secondary Education	(0.652)	(1.000)		
Education									

# Table 4.5: Results of Association between Total Financial Costs, Sociodemographic and Clinical Profile

				Total Fina	ancial Costs				
	Ν	Aedian (IQR)				Pairw	ise Comparisons		
	Breast	Colorectal	Lung	Nasopharyngeal		Breast	Colorectal	Lung	Nasopharyngeal
Kruskal Wallis	0.000*	0.018*	0.638	0.325	Primary Education-	-47.703*	-2.292	-	-
(p-value)					College / University	(0.000)	(1.000)		
					Education				
					Secondary	-31.573*	7.508	-	-
					Education-College /	(0.002)	(1.000)		
					University Education				
				Employn	nent Status				
Working	7,770.50	13,383.50	7,886.00	3,493.25	Retired-Others	-	-	-	-
	(19,103.50)	(26,436.00)	(56,854.50)	(2,741.88)					
Unemployed	6,131.58	6,460.00	5,925.00	7,439.00	Retired-Unemployed	-	-	-	-
	(17,347.50)	(44,145.75)	(7,690.00)	(9,394.00)					
Retired	6,741.00	10,317.50	4,602.00	4,826.00	Retired-Working	-	-	-	-
	(18,418.00)	(13,207.92)	(11,962.00)	(10,546.85)					
Others	5,797.00	11,506.00	4,684.50	5,033.00	Others-Unemployed	-	-	-	-
	(23,834.00)	(18,875.50)	(27,273.10)	(9,152.50)					
Kruskal Wallis	0.667	0.246	0.474	0.185	Others-Working	-	-	-	-
( <i>p</i> -value)									
					Unemployed-	-	-	-	-
					Working				
				Baseline Hou	sehold Income				
Low Income	5,153.00	9,555.00	4,045.00	4,550.00	Low-Income	-0.947	-12.921	-	-
Household (B40)	(12,780.60)	(12,671.00)	(6,119.25)	(4,329.50)	Household-	(1.000)	(0.200)		
					Middle-Income				
					Household				
Median Income	6,579.00	12,093.50	15,449.60	4,797.00	Low-Income	-41.262*	-27.492*	-	-
Household (M40)	(7,618.88)	(28,272.75)	(47,184.20)	(10,996.50)	Household-	(0.000)	(0.005)		
					High-Income				
					Household				
High Income	25,975.98	28,349.25	6,708.00	13,024.00	Middle-Income	-40.315*	-14.571	-	-
Household (T20)	(27,313.00)	(33,310.00)	(80,069.50)	-	Household- High-	(0.001)	(0.402)		
					Income Household				
Kruskal Wallis	0.000*	0.004*	0.070**	0.146		-	-	-	-
( <i>p</i> -value)									

				Total Fina	ancial Costs				
		Media	nn (IQR)			Pairw	ise Comparisons		
	Breast	Colorectal	Lung	Nasopharyngeal		Breast	Colorectal	Lung	Nasopharyngeal
				Cance	r Stages				
Stage I	5,914.30	6,044.00	6,192.50	3,630.00	Stage IV-Stage I	11.562	-15.467	-	-
	(19,851.75)	(8,176.50)	(14,524.50)	(3,491.05)		(1.000)	(1.000)		
Stage II	8,166.00	18,798.00	4,984.50	6,046.00	Stage IV-Stage II	21.915	19.742	-	-
	(20,590.00)	(32,569.50)	-	(9,270.25)		(0.191)	(0.289)		
Stage III	13,080.00	10,765.00	7,886.00	4,583.00	Stage IV-Stage III	31.912*	-1.255	-	-
	(21,603.75)	(13,333.00)	(63,802.90)	(8,706.10)		(0.033)	(1.000)		
Stage IV	3,782.25	8,286.50	4,267.50	4,609.00	Stage I-Stage II	-10.352	-35.209*	-	-
	(3,613.25)	(18,134.50)	(19,407.25)	(14,827.00)		(1.000)	(0.002)		
Kruskal Wallis	0.029*	0.002*	0.882	0.270	Stage I-Stage III	-20.349	-14.211	-	-
(p-value)						(0.303)	(0.735)		
					Stage II-Stage III	-9.997	20.997*	-	-
						(1.000)	(0.021)		
				Treatm	ent Status				
Completed	6,378.00	10,296.00	4,755.00	4,731.70	-	-	-	-	-
Treatment	(20,198.95)	(13,501.00)	(9,542.80)	(5,423.00)					
Ongoing	7,375.00	13,210.50	6,146.00	5,244.00	-	-	-	-	-
Treatment	(15,820.00)	(26,526.25)	(26,844.50)	(23,277.00)					
Mann-Whitney	0.605	0.268	0.942	0.315	-	-	-	-	-
(p-value)									
				Family	' History				
Yes	14,150.60	15,250.00	5,761.50	5,103.55	-	-	-	-	-
	(25,554.50)	(29,427.25)	(8,944.05)	(10,185.75)					
No	5,455.00	10,804.00	5,131.00	4,550.00	-	-	-	-	-
	(14,972.00)	(14,503.50)	(27,440.00)	(3,953.33)					
Mann-Whitney	0.008*	0.302	0.583	0.402	-	-	-	-	-
(p-value)									
				Area of	Residence				
Capital City-	6,213.50	10,296.00	4,755.00	4,064.00	-	-	-	-	-
Kuching	(19,629.00)	(19,147.00)	(28,245.50)	(4,697.00)					
Outside Capital	10,824.00	12,981.50	5,925.00	4,855.00	-	-	-	-	-
City of Kuching	(20,202.93)	(19,287.00)	(9,614.00)	(8421.80)					
Mann-Whitney	0.204	0.210	0.823	0.278	-	-	-	-	-
(p-value)									

				Total Fina	ancial Costs				
		Media	an (IQR)			Pair	wise Comparisons	;	
	Breast	Colorectal	Lung	Nasopharyngeal		Breast	Colorectal	Lung	Nasopharyngeal
				Treatmer	nt Pathway				
Public Hospital	3,811.00	7,660.00	4,755.00	4,609.00	-	-	-	-	-
	(4,628.00)	(10,931.00)	(10,183.50)	(4,640.50)					
Public and Private	24,660.00	35,830.00	109,975.00	12,2625.00	-	-	-	-	-
Hospitals	(22,071.73)	(24,666.50)	-	-					
Mann-Whitney	0.000*	0.000*	0.002*	0.003*	-	-	-	-	-
(p-value)									
				Chemo	otherapy				
Chemotherapy	6,981.50	10,600.00	6,427.00	4,822.00	-	-	-	-	-
(Yes)	(19,461.50)	(14,264.50)	(67,504.70)	(8,266.90)					
Chemotherapy	5,140.00	12,712.00	3,930.00	2,580.00	-	-	-	-	-
(No)	(15,967.75)	(28,040.75)	(6,408.00)	(2,410.00)					
Mann-Whitney	0.127	0.454	0.038*	0.035*	-	-	-	-	-
( <i>p</i> -value)					-				
				Radio	therapy				
Radiotherapy	7,110.16	11,506.00	4,160.00	4,809.50	-	-	-	-	-
(Yes)	(19,609.95)	(28,678.50)	(17,959.00)	(7,121.25)					
Radiotherapy (No)	5,198.60	10,600.00	5,599.50	3,004.00	-	-	-	-	-
	(12,345.25)	(14,083.00)	(14,728.25)	(4,702.45)					
Mann-Whitney	0.180	0.341	0.743	0.091	-	-	-	-	-
( <i>p</i> -value)				~					
				Sur	gery				
Surgery (Yes)	7,110.16	12,282.70	6,347.99	4,491.00	-	-	-	-	-
	(20,121.93)	(20,474.50)	(47,739.20)	(16,,025.00)					
Surgery (No)	4,100.00	6,298.00	4,375.00	4775.00	-	-	-	-	-
	(9,016.00)	(9,297.00)	(14,388.00)	(6,234.50)					
Mann-Whitney	0.020*	0.016*	0.232	0.673	-	-	-	-	-
(p-value)									

Notes: Asterisks (\*) and (\*\*) denote 5% and 10% level of significance, respectively. Abbreviation: IQR, Interquartile Range.

#### 4.6 Level of Financial Toxicity of Cancer Survivors

The score range for Financial Toxicity (COST) is 0 to 44.0. The highest level of financial toxicity is a score of 0 while the lowest level of financial toxicity is a score of 44.0. Scores that range from 23.0 to 44.0 are considered lower levels of financial toxicity whereas higher levels of financial toxicity have scores ranging from 0 to 22.0. Ethnicity, age group, education level, baseline household income, primary cancer site, cancer stages, area of residence, treatment pathway, chemotherapy and surgery had a significant link to financial toxicity.

In general, those below 59 years had a score of 20.0 to 21.0. The cancer survivors aged above 60 tended to have higher financial toxicity scores of 23.0 to 24.5. It can be concluded that younger age groups might earn less income or have less accumulated assets and thus have poorer spending power for cancer treatment (Shankaran et al., 2012). Besides this, younger cancer survivors suffered a 2 to 5 times higher rate of bankruptcy and greater levels of financial toxicity (Kaddas et al., 2020). For all employment statuses, none of the categories had more than 26.0 scores in financial toxicity, this showed that working cancer survivors still suffered from a mild impact on quality of life.

Survivors of cancer with university-equivalent higher education appeared to have lower financial toxicity. This is because people who are more highly educated are more sensitive to cancer health problems. Level of education affects the tumor awareness of patients and their questions about early detection, care and diagnosis (Liu et al., 2017). Apart from this, all cancer sites have an impact on quality of life, where nasopharyngeal cancer was related to the poorest level of quality of life. A decline in the financial toxicity shows that late-stage levels (Stage III and Stage IV) have a higher impact on the quality of life. This was similar with the finding indicated that the majority of nasopharyngeal cancer survivors were diagnosed during later stages especially among Sarawak Indigenous groups. Poor financial ability as farmers decreased the accessibility to earlier medical treatment.

The cancer survivors that received treatment within the Kuching area commonly suffered less financial toxicity compared to those outside the Kuching area who sought treatment. Those who selected the public hospital treatment pathway had higher levels of financial toxicity. This showed the possibility that cancer survivors are from the lower household income group. Higher household spending leads to poor financial ability and accessibility for better care (Ting et al., 2020). In contrast, there was a lower level of financial toxicity for those who received treatment from both public and private hospitals.

Besides this, cancer survivors who went for chemotherapy suffered a higher level of financial toxicity. This was correlated with findings from the 2010 National Health Interview Survey proved that patients treated with chemotherapy claimed to have greater financial difficulties at 47 percent compared to those who did not receive chemotherapy at 31 percent (Kent et al., 2013). In addition, cancer survivors who received surgery treatment had lower financial toxicity scores and a higher quality of life; moreover, it was proven in the study by Wu et al. (2010) suggested that surgical treatment is able to greatly improve quality of life but does not prolong survival. However, this result outcome is inconsistent with Ting et al. (2020). The study demonstrated that cancer survivors suffered from financial burdens after receiving chemotherapy or radiotherapy and other treatment compared to those who underwent surgery.

Another study by Warren et al. (2008) showed that a large portion of Medicare payments for the studied cancers (breast cancer, colorectal cancer and lung cancer) occurred during the initial cancer surgery period. A possible explanation would be that treatment costs were partially or fully covered by health insurance or insurance companies. Other than that, low and middle-income groups suffered greater financial toxicity levels that impact the quality of life. In contrast, the high-income group was free from the burden on quality of life. This means that cancer patients of higher economic status have better access to advanced treatment and recovery. Apart from that, an increased financial burden resulted in worse health-related quality of life and increased symptom burden. This is further shown by a study that demonstrated that colorectal or lung cancer patients have higher financial distress and poorer quality of life (Lathan et al., 2016). Even though we may provide a high quality of cancer care, quality of life in survivors will be poorly affected if there is a failure to manage the resulting financial burden (Rebecca and George, 2019).

Financial Toxicity Score									
		Median (IQR)		Pairwise Comparisons					
	FTS (<=22)	FTS (>22)	FTS (Median)		FTS (<=22)	FTS (>22)	FTS (Median)		
Ethnicity									
Malay	18.50	29.00	21.00	Malay-Sarawak Indigenous	16.426	16.355	24.499		
	(7.00)	(7.00)	(8.50)	group	(0.337)	(0.456)	(0.322)		
Chinese	15.00	34.00	26.00	Malay-Chinese	-34.835*	28.095*	32.059		
	(10.00)	(13.00)	(18.00)		(0.005)	(0.018)	(0.092)		
Sarawak Indigenous	16.50	26.00	20.00	Sarawak Indigenous group-	-18.409	44.451*	56.558*		
group	(8.00)	(10.00)	(9.00)	Chinese	(0.171)	(0.000)	(0.000)		
Kruskal Wallis	0.006*	0.000*	0.000*	-					
(p-value)									
			Age	Group					
Less than 50	16.00	29.50	20.00	Less than 50-50-59	-	9.766	-13.402		
	(8.00)	(9.50)	(12.00)			(1.000)	(1.000)		
50-59	16.50	28.00	21.00	Less than 50-60-69	-	-18.330	-56.880*		
	(8.00)	(8.75)	(12.00)			(0.454)	(0.001)		
60-69	16.00	33.00	24.50	Less than 50-70 and above	-	-13.076	-59.717*		
	(9.00)	(14.50)	(16.75)			(1.000)	(0.011)		
70 and above	19.00	34.00	23.00	50-59-60-69	-	-28.096*	-43.478*		
	(5.00)	(14.25)	(15.00)			(0.3031)	(0.025)		
Kruskal Wallis	0.108	0.032*	0.000*	50-59-70 and above	-	-22.842	-46.315		
(p-value)						(0.456)	(0.106)		
				60-69-70 and above	-	5.254	-2.837		
						(1.000)	(1.000)		
			Educat	tion Level					
No formal Schooling	18.00	26.00	19.00	No formal Schooling-	-	-	-40.382		
	(9.00)	(5.50)	(10.00)	Primary Education			(0.254)		
Primary Education	16.50	32.00	21.00	No formal Schooling-	-	-	-64.384*		
	(9.50)	(16.00)	(11.00)	Secondary Education			(0.001)		
Secondary Education	16.00	31.00	23.00	No formal Schooling-	-	-	-75.118*		
	(7.75)	(12.00)	(15.00)	College / University			(0.005)		
				Education					
College/ University	18.50	31.00	24.00	Primary Education-	-	-	-24.002		
Education	(7.50)	(9.00)	(14.00)	Secondary Education			(0.593)		

## **Table 4.6:** Results of Association between Financial Toxicity, Sociodemographic and Clinical Profile

Financial Toxicity Score								
		Median (IQR)		Pairwise Comparisons				
	FTS (<=22)	FTS (>22)	FTS (Median)		FTS (<=22)	FTS (>22)	FTS (Median)	
Kruskal Wallis	0.774	0.338	0.001*	Primary Education-College	-	-	-34.736	
(p-value)				/ University Education			(0.496)	
				Secondary Education-	-	-	-10.734	
				College / University			(1.000)	
				Education				
			Employr	nent Status				
Working	16.50	29.00	24.00	Retired-Others	-	-	-	
	(8.00)	(10.00)	(14.00)					
Unemployed	17.00	31.00	21.00	Retired-Unemployed	-	-	-	
	(6.50)	(12.50)	(14.00)					
Retired	16.00	30.00	22.00	Retired-Working	-	-	-	
	(9.50)	(12.25)	(14.00)					
Others	16.00	31.00	21.00	Others-Unemployed	-	-	-	
	(8.50)	(10.75)	(14.00)					
Kruskal Wallis	0.783	0.909	0.427	Others-Working	-	-	-	
( <i>p</i> -value)								
				Unemployed-Working	-	-	-	
			Baseline Hou	isehold Income				
Low Income Household	16.00	28.00	20.00	Low-Income Household-	-	-22.968*	-72.751*	
(B40)	(8.00)	(11.00)	(10.00)	Middle-Income		(0.032)	(0.000)	
				Household				
Median Income	17.50	32.00	25.00	Low-Income Household-	-	-30.996*	-116.540*	
Household (M40)	(6.50)	(15.00)	(15.50)	High-Income Household		(0.006)	(0.000)	
High Income Household	20.00	33.00	31.00	Middle-Income Household-	-	-8.028	-43.790	
(120)	(8.25)	(12.00)	(14.00)	High-Income Household		(1.000)	(0.075)	
Kruskal Wallis	0.146	0.003*	0.000*					
(p-value)				<u>a</u> at				
	17.50	20.50	Primary	Cancer Site		22.1.62	0.0.07	
Breast	17.50	30.50	22.00	Nasopharyngeal-Lung	-	32.163	26.367	
	(8.00)	(10.00)	(12.75)	N. I. I.D.		(0.148)	(1.000)	
Colorectal	1/.00	52.00	24.00	Nasopharyngeal-Breast	-	22.755	40./08	
I	(8.00)	(13.00)	(15.00)	Nasarhammaral Calassi I		(0.291)	(0.062)	
Lung	16.00	30.00	21.00	Nasopharyngeal-Colorectal	-	3/.185*	53.020*	
	(7.00)	(11.00)	(14.00)			(0.011)	(0.010)	

Financial Toxicity Score									
		Median (IQR)							
	FTS (<=22)	FTS (>22)	FTS (Median)		FTS (<=22)	FTS (>22)	FTS (Median)		
Nasopharyngeal	14.00	25.00	20.00	Lung-Breast	-	-9.409	14.342		
	(9.25)	(11.25)	(11.00)			(1.000)	(1.000)		
Kruskal Wallis	0.158	0.016*	0.012*	Lung-Colorectal	-	5.022	26.653		
( <i>p</i> -value)						(1.000)	(0.830)		
				Breast-Colorectal	-	-14.430	-12.312		
						(0.745)	(1.000)		
			Cance	r Stages					
Stage I	16.00	29.00	23.00	Stage IV-Stage I	-	-	39.118		
	(8.00)	(12.00)	(13.50)				(0.118)		
Stage II	18.00	33.00	23.00	Stage IV-Stage II	-	-	50.122*		
	(10.00)	(14.00)	(15.50)				(0.008)		
Stage III	16.00	29.00	22.00	Stage IV-Stage III	-	-	30.321		
	(6.75)	(11.00)	(13.00)				(0.320)		
Stage IV	16.00	29.00	20.00	Stage I-Stage II	-	-	-11.003		
	(8.00)	(8.75)	(12.50)				(1.000)		
Kruskal Wallis	0.829	0.760	0.011*	Stage I-Stage III	-	-	8.797		
(p-value)							(1.000)		
				Stage II-Stage III	-	-	19.800		
							(1.000)		
			Family	' History					
Yes	15.00	29.00	23.50	-	-	-	-		
	(7.00)	(10.00)	(14.25)						
No	17.00	31.00	21.00	-	-	-	-		
	(8.00)	(13.00)	(13.00)						
Mann-Whitney	0.357	0.591	0.208	-	-	-	-		
( <i>p</i> -value)									
			Area of	Residence					
Capital City-Kuching	18.00	31.00	23.00	-	-	-	-		
	(8.00)	(11.00)	(13.00)						
Outside Capital City of	15.00	29.00	20.50	-	-	-	-		
Kuching	(7.00)	(14.00)	(13.00)						
Mann-Whitney	0.080	0.141	0.015*	-	-	-	-		
(p-value)									

Financial Toxicity Score									
	Ν	Median (IQR)			Pairwise Comparisons				
	FTS (<=22)	FTS (>22)	FTS (Median)		FTS (<=22)	FTS (>22)	FTS (Median)		
Treatment Pathway									
Public Hospital	16.00	29.00	21.00	-	-	-	-		
	(8.00)	(11.00)	(12.75)						
Public and Private	18.00	32.50	26.00	-	-	-	-		
Hospitals	(9.50)	(12.50)	(13.75)						
Mann-Whitney	0.378	0.116	0.000*	-	-	-	-		
(p-value)									
			Chemo	otherapy					
Chemotherapy (Yes)	16.00	31.00	21.00	-	-	-	-		
	(8.00)	(11.00)	(14.00)						
Chemotherapy (No)	18.00	29.50	23.50	-	-	-	-		
	(7.25)	(13.25)	(13.00)						
Mann-Whitney	0.486	0.661	0.030*	-	-	-	-		
(p-value)									
			Radio	therapy					
Radiotherapy (Yes)	17.00	30.00	21.50	-	-	-	-		
	(8.00)	(11.00)	(12.75)						
Radiotherapy (No)	16.00	31.50	22.50	-	-	-	-		
	(8.75)	(11.75)	(15.75)						
Mann-Whitney	0.663	0.055	0.228	-	-	-	-		
(p-value)									
			Sur	gery					
Surgery (Yes)	17.00	31.00	22.50	-	-	-	-		
	(8.00)	(11.00)	(14.00)						
Surgery (No)	16.00	26.50	21.00	-	-	-	-		
	(8.00)	(12.00)	(11.00)						
Mann-Whitney	0.898	0.017*	0.033*	-	-	-	-		
( <i>p</i> -value)									

Note: Asterisk (\*) denotes 5% level of significance. Abbreviations: FTS, Financial Toxicity Score and IQR, Interquartile Range.

#### 4.7 Work Productivity of Cancer Patients

The annual average loss of productivity in the form of money is demonstrated in Figure 4.12. The productivity measurement is based on the human capital approach. It caused on average a loss of RM10,910.80 per individual per year, based on the presenteeism approach. Instead, based on the absenteeism method, cancer causes a loss of income of RM17,740.17 each year. People who are faced with loss of work (from reduced work to unemployed) due to disease, also known as temporary workforce absenteeism, suffered losses of RM43,370.12 per year. Early retirement which denotes individuals who are pre-retired (60 years) causes a loss of RM252,674.29.



Absenteeism Presenteeism Temporary Workforce Absenteeism Early retirement
 Figure 4.12: Average Productivity Loss Per Person (RM)

Table 4.7 indicates the total productivity loss per individual in one year. In terms of both average and annual productivity loss for low-income household, they tend to have lesser loss for neither absenteeism nor presenteeism, but greater loss compared

to high-income household for early retirement in general as shown in Figure 4.12. Low-income families are usually earned by payday and might not be able to work during the recovery period. This might cause a loss in terms of daily paid, especially if the patients were the responsible person to earn.

Annual Productivity Loss Per Person (RM)										
Income Group	Absenteeism	Presenteeism	Temporary workforce absenteeism	Early retirement						
Low Income Household (B40)	7,745.39	3,786.23	16,571.73	24,448.00						
Middle Income Household (M40)	17,555.01	5,441.47	19,008.00	28,080.00						
High Income Household (T20)	6,620.30	22,758.07	24,000.00	30,000.00						
Total	11,676.94	5,767.45	16,956.24	25,577.14						

 Table 4.7: Results of Annual Productivity Loss Per Person (RM)

On the other hand, there is a strong correlation between employment and absenteeism rates, as shown in Table 4.7. Staff in the public sector showed a greater loss of productivity as public servants are able to enjoy paid medical leave and a maximum of 2 years recovery period from the disease. In terms of absenteeism, baseline household income showed significant losses. The high-income group had a higher absenteeism rate than the low-income group and preferred longer medical leave due to lesser financial burden and stress. Indeed, cancer stages and primary cancer site had statistically significant effects.

Work Productivity									
	Μ	ledian (IQR)			Pairwise Comparisons				
	Absenteeism	Presenteeism	Early	Temporary		Absenteeism	Presenteeism	Early	Temporary
			Retirement	Workforce				Retirement	Workforce
				Absenteeism					Absenteelsm
Dublia Hamital	10 409 99	2 017 65	26,000,00	Етрюу	ment Sector				
Public Hospital	10,498.88	3,917.05	30,000.00	-	-	-	-	-	-
Dublic and Driveto	(20,714.00)	(7,880.00)	18,000,000	14 400 00					
	(1.620.00)	(5152.00)	(15,000.00)	(16.056.00)	-	-	-	-	-
Mann Whitney	(1,029.00)	(3132.00)	(13,000.00)	(10,050.00)					
( <i>n</i> -value)	0.000*	0.395	0.088	-	-	-	-	-	-
(p-value)				<b>Baseline H</b> o	usehold Income				
Low Income	663.73	1.663.64	17.520.00	12.000.00	Low-Income	-16.639	-	-	-
Household (B40)	(3.175.00)	(5.250.00)	(15.600.00)	(16.800.00)	Household-	(0.060)			
	(0,0000)	(0,20000)	(,)	(,,	Middle-Income	(00000)			
					Household				
Median Income	2,618.18	2,786.34	22,800.00	14,400.00	Low-Income	-21.798*	-	-	-
Household (M40)	(17,313.00)	(2,694.00)	(18,000.00)	(27,360.00)	Household-	(0.005)			
					High-Income				
					Household				
High Income	3,640.00	6,109.09	63,000.00	24,000.00	Middle-Income	-5.159	-	-	-
Household (T20)	(11,988.00)	(30,419.00)	-	-	Household- High-	(1.000)			
					Income Household				
Kruskal Wallis	0.003*	0.440	0.138	0.125					
( <i>p</i> -value)									
D	1.006.00	1.660.45	15 500 00	Primary	Cancer Site				
Breast	1,096.30	1,669.45	17,520.00	10,800.00	Nasopharyngeal-Lung	-	-	-	-
C 1	(10, /52.00)	(5,284.00)	(44,400.00)	(15,648.00)	N. I. D. (				
Colorectal	1,623.29	1,541.28	19,200.00	13,200.00	Nasopharyngeal-Breast	-	-	-	-
Lung	(0,055.00)	(3,440.00)	(13,200.00)	(25,500.00)	Nacanharmagal				
Lung	4,113.04	3,000.00	30,000.00	14,400.00	Rasopharyngeal-	-	-	-	-
Nasonharangaal	(18,070.00)	(3,312.00)	(31,200.00)	(12,000.00)	Lung Breast				
Nasopharyngeal	3,000.00	0,230.00	(10,200,00)	(30,000,00)	Lung-Dreast	-	-	-	-
	(27,203.00)	-	(19,200.00)	(30,000.00)					

## **Table 4.8:** Results of Association between Work Productivity, Sociodemographic and Clinical Profile

Work Productivity									
	Μ	ledian (IQR)			Pairwise Comparisons				
	Absenteeism	Presenteeism	Early	Temporary		Absenteeism	Presenteeism	Early	Temporary
			Retirement	Workforce				Retirement	Workforce
				Absenteeism					Absenteeism
Kruskal Wallis	0.326	0.3698	0.988	0.694	Lung-Colorectal	-	-	-	-
( <i>p</i> -value)									
					Breast-Colorectal	-	-	-	-
				Cano	er Stages				
Stage I	2,186.05	634.62	-	14,400.00	Stage IV-Stage I	-	-	-	-
	(13,613.00)	(8,669.00)		(16, 500.00)					
Stage II	1,000.00	2,247.41	-	9,300.00	Stage IV-Stage II	-	-	-	-
	(6,755.00)	(4,722.00)		(23,400.00)					
Stage III	1,314.29	2,592.00	22,800.00	18,000.00	Stage IV-Stage III	-	-	-	-
	(23,264.00)	(4,644.00)	(20, 400.00)	(18,000.00)					
Stage IV	6,458.82	2,520.00	17,520.00	12,000.00	Stage I-Stage II	-	-	-	-
	(31,862.00)	(3,743.00)	(21,600.00)	(12,600.00)					
Kruskal Wallis	0.260	0.488	0.798	0.507	Stage I-Stage III	-	-	-	-
( <i>p</i> -value)									
• /					Stage II-Stage III	-	-	-	-

Notes: Asterisks (\*) and (\*\*) denote 5% and 10% level of significance, respectively. Abbreviation: IQR, Interquartile Range.

#### 4.8 Predictors of Financial Toxicity: Binary Logistic Regression

Binary logistic regression was used to determine the predictors of financial toxicity. In this study, the relationship between one or more explanatory variables and a single output binary variable was determined by binary logistic regression. The results in Table 4.9 indicate an increased probability of financial toxicity for all age groups and all education levels. The treatment pathway increases the probability of financial toxicity for cancer survivors receiving treatment in public and private hospitals. Approximately 38.8% of the patients who received treatment from both public and private hospitals were from high-income households and 70.1% of cancer survivors from the low-income group were mainly treated in public hospitals. A closer look at the drivers of financial toxicity among the cancer survivors revealed that 74.8% of cancer survivors from the low-income group experienced a higher level of financial toxicity and a lower quality of life.

The odds ratio value of 1 indicates no relationship between the predictor; more than 1 indicates there is a positive relationship between the predictor and the independent variable and odds ratio less than one fails to predict the financial toxicity. In addition, the value can be associated with the regression coefficient. For categorical predictors, the odds ratio compares the 2 different levels of financial toxicity. The odds ratio that is greater than 1 indicates lower financial toxicity whereas odd ratios less than 1 indicate higher financial toxicity. The determinant of financial toxicity will be presented below.

The odds ratio for those aged 50 to 59, 60 to 69 and 70 and above was 1.735, 4.978 and 6.019 respectively, indicating those in the 50-59 age group have two times lower financial toxicity; those in the 60-69 have five times lower financial toxicity and those 70 years old and above have six times lower financial toxicity compared to those aged 50 years and below. On the other hand, the odds ratio for those with primary education, secondary education and college/ university education was 2.527, 6.112 and 7.961 respectively indicating that those with primary education have 3 times lower financial toxicity; those with secondary education have 6 times lower financial toxicity and those with a university-equivalent education and college have 8 times lower financial toxicity compared to those who have no formal schooling. The other factors were insignificant in the final logistic model. The result of Hosmer-Lemeshow test showed acceptable goodness of fit for the model. Nagelkerke  $R^2$  provides a clearer definition: it is the proportion of the variation in the dependent variable that can be explained by predictors in the model. A *p*-value lower than 0.05 is considered meaningful.

Variables	Adjusted	95% CI	95% CI	<i>p</i> -value
	OR	(Lower)	(Upper)	
	Age Group			
Less than 50	1.000			
50-59	1.735	0.978	3.080	0.060*
60-69	4.978	2.636	9.402	0.000*
70 and above	6.019	2.610	13.884	0.000*
	<b>Education lev</b>	el		
No formal Schooling	1.000			
Primary Education	2.527	1.096	5.826	0.030*
Secondary Education	6.112	2.729	13.685	0.000*
College / University Education	7.961	2.895	21.892	0.000*

 Table 4.9: Binary Logistic Regression Results

Variables	Adjusted	95% CI	95% CI	<i>p</i> -value				
	OR	(Lower)	(Upper)					
Cancer Stages								
Stage I	1.000							
Stage II	1.027	0.542	1.946	0.934				
Stage III	0.814	0.431	1.538	0.527				
Stage IV	0.516	0.268	0.992	0.047*				
T	reatment Path	way						
Public Hospital	1.000							
Public and Private Hospitals	1.859	1.043	3.313	0.035*				
Model Coefficient	X <sup>2</sup>	(10) = 65.35	57, p= 0.000					
Nagelkerke $R^2$	0.207							
Hosmer and Lemeshow Test	<i>p</i> =0.863							

Note: Asterisks (\*) denotes the significance at 5% level of significance. Abbreviation: OR, Odds ratio

#### 4.9 Concluding Remarks

The purpose of this study is to analyze the economic burden of cancer survivors in Sarawak. This research was conducted on four specific cancers such as breast cancer, colorectal cancer, lung cancers, and nasopharyngeal cancer in the Radiotherapy, Oncology, and Palliative Care unit, Sarawak General Hospital. The survey took approximately 5 months for data collection. This study recruited a total of 388 survivors of cancer. There were 144 breast cancer survivors, 107 colorectal cancer survivors, 61 lung cancer survivors and 76 nasopharyngeal cancer survivors. This study's empirical results are divided into four main sections: financial cost of cancer, level of financial toxicity and work productivity of cancer survivors, and the binary regression analysis.

### CHAPTER 5 CONCLUSION AND POLICY IMPLICATIONS

#### 5.0 Introduction

This chapter discusses the economic burden of cancer survivors. It starts with a summary of empirical findings that collected from survey outcomes. Subsequently, the policy implications and recommendations will be discussed. This chapter also includes the limitation and recommendations for future study. Lastly, this chapter ends with a conclusion.

#### 5.1 Summary of Empirical Findings and Discussion

The aim of this research is to ascertain the burden of survivors of cancer. In the Department of Radiotherapy, Oncology and Palliative Treatment in Sarawak General Hospital, a total of 388 survivors of four different cancers were recruited. Of these 388 breast cancer survivors, 144 were breast cancer survivors and 107 or 27.6% were colorectal cancer survivors. Lung cancer accounted for 61 or 15.7%, whereas nasopharyngeal cancer accounted for 76 or 19.6%. Cancer survivors with education levels equivalent to college or university education tended to spend more on breast and colorectal cancer. This is in line with the inference from this study which stated patients with higher education attainment are more prone to health issues in relation to cancer. The degree of education influences the patient's tumor understanding and concerns for early detection, treatment, and diagnosis (Liu et al., 2017).

Cancer survivors from the high-income household group were recognized as having the highest spending on total core therapy, total follow-up costs and total financial costs for breast and colorectal cancer. Besides, the spending on non-medical costs, particularly for breast cancer, reflects that cancer survivors from high-income groups invested more in care, follow-up or additional therapy or medication for improved living conditions. This also reduces the waiting time for treatment and secures efficient recovery, leading to less impact on the quality of life and lower financial toxicity. The median household income from this study was RM2,500 [interquartile range (IQR) = 3,800], which falls into the Bottom 40 group (less than RM4,850) as reported in the Household Income and Basic Amenities Survey Report 2019. This reveals that most of the studied respondents had little ability to afford expensive medical treatment and therapy.

Those of Chinese ethnicity spent the most on overall costs for breast and colorectal cancers' core treatment. They tended to spend more than other groups because half of the survivors were from middle and high-income groups with better financial ability. Besides this, Chinese, in general, spend most on non-medical costs for colorectal cancer care. Both breast and colorectal cancer care imposed a massive burden on Chinese for advanced cancer examination and surgery at private hospitals to speed up the treatment. This is because of the massive impact and spending are found on colorectal cancer survivors during Stage II. In contrast, breast cancer survivors suffer a massive impact and spending during late stages (Stage III and Stage IV) when aggressive treatment to prevent cancer and disease risks is required.

Lung cancer is detected late with low healing rates among cancer patients. The finding indicates that 77.1 percent of lung cancer survivors were found at later stages

because of difficulties in recognizing warning signals. Additionally, aggressive medication and frequent monitoring are needed to monitor and combat the cancer cells which leads to a rise in annual cost of core care and non-medical services. Besides this, many nasopharyngeal cancers were identified in stage IV. The majority of nasopharyngeal cancer survivors interviewed were from the Bidayuh tribe outside Kuching where traveling long distances required extra spending which in turn increased their financial burden.

Across Malaysia, public health facilities are almost free of charge and only some services require nominal charges for out-of-pocket expenditure (OOP). However, the amount of OOP costs incurred by cancer patients is still considerably high for a costly and prolonged illness such as cancer. Even though costs are heavily subsidized in public hospitals, cancer may still lead to various catastrophic economic impacts on patients and their families (Azzani et al., 2017). These costs may also contribute to poverty for these patients, especially core therapy and follow-up therapy. This study also attempted by quantification of both direct and indirect cost data, to determine the full cost. Depending on the results, late-stage cancer survivors spend more on cancer treatment costs than earlier-stage cancer survivors. The predominance of cancer diagnosis in the late stages (III and IV) also correlates to the findings of the latest Cancer National report in Malaysia. This increases the possible financial burden, considering that cancer treatment costs are higher in Stage III and IV than in Stages I and II. These results illustrate the need for early cancer treatment approaches that reduce the patient's usage of health care services to prevent financial catastrophes. The OOP expenses is also another crucial issue for cancer survivors who already face financial obstacles to medical treatment at the point of treatment and services.

Compared to survivors who receive therapy in fully public hospitals, the expenditure of patients who choose the treatment pathway in both public and private hospital is relatively high. This has shown that the care and rehabilitation costs for private hospitals are higher. Even so, the cancer survivors with higher financial ability prefer private hospitals due to the general perception on private hospitals (short waiting time and a more effective recovery rate). For those who stay in Kuching or outside Kuching, no significant difference was found. Besides this, radiation therapy is vital for lung and nasopharyngeal cancer survivors, whereas surgery was statistically shown to be more effective for breast and colorectal cancer. It was shown that all patients with lung cancer continued to be exposed to bundled follow-ups due to the late-stage treatments and the need for intensive monitoring and testing. The use of stoma, ostomy, and dietary goods for the patient's lifetime also puts additional spending pressures on families. The survivors of nasopharyngeal cancers spent more on non-medical expenses during or after radiation treatments.

Besides this, cancer survivors that go for chemotherapy suffered a higher level of financial toxicity. This correlates with the study by Kent et al. (2013) and Wu et al. (2010) but is inconsistent with Ting et al. (2020). Another study by Warren et al. (2008) showed that many Medicare payments for the studied cancers were during the initial cancer surgery period. Perhaps the higher quality of life achieved after surgery due to partial of full coverage of insurance or other financial support results in lower financial toxicity. Apart from this, greater levels of financial toxicity impact quality of life among low and middle-income groups, resulting in poor financial ability and accessibility to cancer care. A study by Lathan et al. (2016) also stated that colorectal or lung cancer patients have higher financial distress and poorer quality of life.

#### **5.2** Policy Implications and Recommendation

The cancer trajectory causes increased out-of-pocket expenditure, reduced functional well-being, a decline in work performance and income losses (World Health Organization [WHO], 1999; Xu et al., 2003). Based on the findings, late stages of cancer presentation tend to have greater spending on the cost of cancer care as well as higher levels of financial toxicity. Thus, the **first policy implication** is to implement subsidized national programs targeting health screening based on various risk factors for cancer. This program should aim to ensure that more people are screened for certain cancer risk factors, resulting in early detection of cancer-related illness. Early detection could secure higher survival rates as well as lower the cost of cancer care. Furthermore, subsidized national health screening programs also open the door for minority and vulnerable groups in the State to obtain better health attention. Therefore, prevention care could provide a better standard of living to these people when their health condition can be well-addressed in a timely manner.

On the other hand, it was found that cancer survivors who received college or university education spent relatively more on overall spending on breast cancer than cancer survivors who achieved primary or secondary education or no formal schooling. They also appear to have a lower financial toxicity. This showed that higher education
levels and better understanding and awareness of health lead to early diagnosis. Therefore, the **second policy implication** is increasing public awareness toward cancer prevention and control by the Ministry of Health as well as agencies and NGOs. Public awareness on cancer can also be addressed through health education to educate the public about the risk factors of different cancer types, cancer treatment, hidden financial burdens, and cancer survivor coping strategies. Better public-private collaboration in community health programs to enhance and promote cancer prevention and early detection is needed. As such, community health programs can be designed in collaboration with private corporations, religious organizations, local healthcare providers as well as cancer societies to offer more concerted programs that support prevention and early detection of cancer including setting voluntary screening clinics, nutrition counseling, cancer support groups and knowledge sharing series on important cancer-related topics. This kind of collaboration is crucial to cultivate a healthy lifestyle and to mitigate risky behaviors such as smoking, harmful use of alcohol or drugs and poor dietary habits.

Furthermore, the study suggests that cancer has important effects on the productivity of the survivors' work. Loss of productivity due to cancer can be significant. Likewise, returning to work for cancer survivors is another tough phase because of its side effects, cognitive disability, cancer complications, and working conditions. The **third policy implication** is that it is crucial to develop a support system to assist cancer survivors either in getting back to work after the cancer treatment or in coping with the disease burden of cancer for those who are still working during the cancer treatment. For instance, a program of support may involve the return

to work and facilitation of the doctor-controversy to investigate patients' ability to return to work. This project can be accomplished by public-private collaboration. Additionally, another policy implication related to work productivity is that it is important to evaluate potential value related to research and development (R&D) of new oncology drugs to impact work productivity. However, baseline data on the potential value of new drugs towards productivity is almost non-existent. Hence, the **fourth policy implication** is, therefore, that a national baseline data on loss of productivity due to cancer treatment is urgently needed. This national baseline data availability would ensure an equitable and accessible value-based cancer drug for all communities.

The study also found that financial toxicity can be huge due to treatment for cancer and long-term monitoring. Higher level financial toxicity is found in public hospitals even though most of the cost is subsidized by government. Based on the findings, the highest financial toxicity burden was experienced by cancer survivors from low-income household groups, with low educational attainment, who were of younger age (< 50 years old) and resided outside the capital city. Therefore, **fifth policy implication** is that healthcare protection for these groups is essential to minimize their financial burden such as Skim Peduli Kesihatan (PeKa B40) and My Salam. However, the protection scheme must be evaluated regularly to ensure the scheme's effectiveness by considering the disparities in social determinants.

#### 5.3 Limitation and Recommendation for Future Study

The survey was a one-off interview conducted in a single session based on selfreported data. However, the self-reported financial expense results are usually smaller, because the government subsidizes most expenses in public hospitals. Another limitation is that, partially or fully, cancer survivors recruited from the public hospital are not receiving full treatment and care in private hospitals. This leads to an underestimation of the overall economic burden of cancer care. In the future study, the cost of cancer treatment in both public and private hospitals should be studied. Both the individual and hospital perspectives should be considered to compute the economic burden associated with the actual costs for cancer treatment. Moreover, it may be worthwhile to quantify the lifetime costs of follow up for a longer time. Thus, research to access cancer patients' lifetime costs in Malaysia is suggested.

In addition, the indirect costs of the loss of productivity of cancer survivors is likely to be underestimated. This is due to some of them not revealing their real income. Only revealed incomes were tabulated whereas the unrevealed incomes were considered missing data. Furthermore, the economic burden of cancer is calculated subjectively (quantitatively) in this study. However, in statistical analysis, it is difficult to discover all issues to provide the real value. Further research may also explore a mixture of qualitative and quantitative (mixed mode) approaches. A qualitative approach (e.g. in-depth interview) can be used to determine how financial toxicity affects cancer survivors' everyday lives. As such, heterogeneous purposive samples taken from the study will provide insight into the economic burden of cancer treatment in Sarawak. Medical complexity such as type of cancer, cancer stage and treatment types, however, is not wellsegmented into broad data subgroups. It is less appropriate to offer a robust view of problems related to a particular cancer to support clinical decisions. Further research may include extending the research into cancer homogeneity. On the other hand, the burden of cancer is not only objective financial burden but also includes subjective financial burden in terms of psychosocial effects among cancer patients and caregivers. Caregivers are commonly spouses, family members and friends, who tend to have the closest relationship with the cancer survivors. The role of caregivers after the patient's treatment along with their fear and pain tend to have a great impact on the overall quality of life.

Ultimately, the survival of cancer is a long riddled with side effects and consequences. The research should extend to longitudinal research to capture changes in quality of life and financial toxicity, whereas this study is a one-off interview only. Other than that, the employability improvement, early pension, premature death, job performance and changes in income were commonly questioned in terms of employment efficiency. The study also highlighted the high levels of financial toxicity among cancer survivors although even with high subsidization in the public hospital. Cancer survivors with lower education levels and income earned as well as those staying outside the capital city are the vulnerable groups who tend to suffer greater financial distress. Thus, it is urged that policymakers and healthcare

agencies implement better financial protection strategies to support these vulnerable groups.

### 5.4 Closing Remarks

The goals of this research have been fully accomplished by the empirical results. The approximate cost of cancer medical treatment is highly predicted for the age group, level of education, cancer stages and pathway of treatment. The approximate loss of productivity is also measured in the monetary terms and further addressed the effect of cancer on working performance. Highly financially toxic and financially difficulties overall are from young cancer survivors under the age of 50. The majority of respondents seeking care came from low middle-income classes and received treatment in public hospitals. Late stage patients must undergo further treatment and additional spending that in return raise their level of financial toxicity and lower the quality of life.

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### Appendixes

### Appendix A (NMRR Approval Letter)

Rujukan kami: UNIMAS/FEB/44107/01 Tarikh: 12 Desember 2018

Dr. Chin Zin Hing Pengarah Hospital Hospital Umum Sarawak Jalan Hospital, 93586 Kuching, Sarawak.

YBhg Dato' / Tuan / Puan:

#### PERMOHONAN KEBENARAN PENGGUNAAN HOSPITAL UMUM SARAWAK UNTUK MENJALANKAN PENYELIDIKAN

Dengan hormatnya: saya merujuk kepada perkara tersebut di atas.

 Saya pertu mengguriskan fasiliti Y8hg Dato//Tuan/Puan untuk aktiviti penyelidikan bertajuk, "NMRR-18-2696-44107-Psychosocial and Economic Impact of Cancer in Malaysia", Penyelidikan ini teleh diuluskan oleh Jawatankuasa Etika Penyelidikan Perubatan JEPP (Medical Research Ethics Committee MREC). Bersama-sama ini disertakan surat kebenaran MREC (Lampiran 1) dan kertas kajan (protocol) / maklumen ringkas projek (Lampiran 2).

 Fasihti/Jabatan di tempat YBhg Dato//Tuan/Puan yang diperlukan adalah seperti berikut:

1. Unit Radioterapi, Onkologi dan Jagaan Paliatif

ii. Wad Onkologi Hospital Umum Sarawak

 Aktiviti penyelidikan yang akan dijalankan di fasiliti YBhg Dato' / Tuan / Puan adatah seperti berikut;

1. Pengumpulan data melalui kajian soal selidik

Kami berharap mendapat kebenaran Y8hg Dato' / Tuan / Puan.

Sekian, terma kasih.

Saya yang manunut perintah,

8WI (Dr. Shirty Wang Saw Ling)

S.k. Assure Deal Michael

Assoc. Prof. Michael Tinggi, Cekan Fakulti Ekonomi dan Pemiagaan Dr. Voon Pel Jye, Radiotorapi, Crikologi & Jagaan Palatif Prof. Dr. Chew Keng Sheng, Fakulti Perubatan dan Sains Kesihatan Dr. Jerome Kueh Swee Hai, Fakulti Ekonomi dan Pemiagaan Ms. Yap Shee Ling, Fakulti Ekonomi dan Pemiagaan pr Veen PJ

for your comment & filing of Oppondix 5(1)

DR. CHIN ZIN HING PENGARAH HOGPITAL UMUM SARANAWA MMC NO. 27035

Revision 1/2015

Page 1



JAWATANKUASA ETIKA & PENYELIDIKAN PERUBATAN (Medical Research & Ethics Committee) KEMENTERIAN KESIHATAN MALAYSIA (Valinsčiut Fengurusan Kesihatan Jalan Rumah Sakit, Bangsar (val. 00-22574 59000 Kuals Lumpur 03-22574



 18.: 00-2257 4782/0282 0401 0282 2485 03-2252 4022/0282 1470/0282 1440
 1948 - 00-2382 0015

Ruj.Kami : KKM.NIHSEC. P1B-2042 (15.)

#### DR SHIRLY WONG SIEW LING UNIVERSITY MALAYSIA SARAWAK (UNIMAS)

YBhg. Date' / Tuan / Puan,

#### SURAT KELULUSAN ETIKA: NMRR-18-2686-44107 (IIR) PSYCHOSOCIAL AND ECONOMIC IMPACT OF CANCER IN MALAYSIA

Lokasi Kajian:

#### HOSPITAL UMUM SARAWAK

Dengan horntatnya perkara di atas adalah dirujuk.

 Jawatankuasa Euka & Penyelidikan Perubatan (JEPP), Kamentarian Kesihatan Malaysia (KKM) tiada halangan, dari segi etika, ke atas pelaksanaan kajian tersebut. JEPP mengambili maklum bahawa kajian tersebut hanya melibatkan pengumpulan data melalui:

- i. Temubual
- ii. Borang soal selidik

 Segata rekod dan date subjek adalah SULIT dan hanya digunakan untuk tujuan kajian ini dan semua isu serta prosedur mengenai *data confidentiality* mesti digatuhi.

4. Kobenaran daripada Pegawai Kesihatan Daerah / Pengarah Hospital dan Ketua-Ketua Jabatan atau pegawai yang bertanggungjawab disetiap lokasi kajian di manakajian akan dijalankan mosti diperolehi sebelum kajian dijalankan. YBhg. Dato' / Tuan / Puan perlu akur dan mematuhi keputusan tersebut. Sila rujuk kepada garis panduan Institut Kesihatan Negara mengenai penyelidikan di Institusi dan fasiliti Kementerian Kesihatan Malaysia (Pindaan 01/2015) serta lampiran Appendix 5 untuk templet surat memohon kebenaran tersebut.

 Adatah cimaktumkan bahawa kelutusan ini adatah san sehingga 2 4 -Oktober-2019. YBhg. Dato'/ Tuan/ Puan pertu menghantar dokumen-dokumen seperti berikut setepas mendapat kelutusan etika. Borang-borang berkaitan boleh dimuat turun daripada taman web Jawatakuasa Etika & Penyelidikan Perubatan (JEPP) (<u>http://www.nih.gov.mv/mrec</u>). KKM.NIHSEC. P18-2042 ( 5 )

- Continuing Review Form selewat-lewatnya dalam tempoh 1 bulan (30 hari) sebelum tamat tempoh kalu usan ini bagi memperbaharui kalulusan otika.
- ii. Study Final Report pada penghujung kajian
- iii. Mendapat kalulusah alika sekiranya terdapat pindaan ko atas sebarang cokumen kajian / lokasi kajian / penyelulik.

 Sila ambil maklum bahawa sebarang urusan surat-menyurat berkaitan dongan penyelidikan ini haruslah dinyatakan nombor rujukan surat ini untuk meticinkan urusan yang berkaitan.

Sekiar terima kasih.

#### "BERKHIDMAT UNTUK NEGARA"

Saya yang menjalapikan amanah.

Salin

(DR H.UK SALINA ABDUL AZIZ) Pengérusi Jawatankuasa Etika & Penyeliolikan Perubatan Kementerian Kesihatan Malaysia mecseo@nih.gov.my 03-2282 9085

s.k.: HRRC Hospital Umum Sarawak

VA7/Approve 2018/Mrecahere

### **Appendix B (Research Protocol and Instrument)**

#### PARTICIPANT INFORMATION SHEET AND INFORMED CONSENT FORM

(for adult subjects and interventional studies)

- **1. Title of research project**: *Psychosocial and Economic Impact of Cancer in Malaysia*
- **2. Name of investigator and institution:** *Dr Shirly Wong Siew Ling, Universiti Malaysia Sarawak*
- 3. Name of sponsor: -

#### 4. Introduction:

You are invited to participate in a research study because you are one of the cancer patients that been undergoes medical treatment. The details of the research trial are described in this document. It is important that you understand why the research is being done and what it will involve. Please take your time to read through and consider this information carefully before you decide if you are willing to participate. Ask the study staff if anything is unclear or if you like more information. After you are properly satisfied that you understand this study, and that you wish to participate, you must sign this informed consent form.

Your participation in this study is voluntary. You do not have to be in this study if you do not want to. You may also refuse to answer any questions you do not want to answer. If you volunteer to be in this study, you may withdraw from it at any time. If you withdraw, any data collected from you up to your withdrawal will still be used for the study. Your refusal to participate or withdrawal will not affect any medical or health benefits to which you are otherwise entitled.

This study has been approved by the *Medical Research and Ethics Committee*, Ministry of Health Malaysia.

#### 5. What is the purpose of the study?

The purpose of this study is to analyze the economic impact of cancer that focus on cancer survivors in both public and private hospitals. This research is necessary because it able to illustrate how big the loss on the economic impact on the individual and families as they been diagnosed in cancer treatment.

## 6. What are the inclusion and exclusion criteria of the study subjects?

A total number of 354 respondents will be recruited over a period of 9 months in Sarawak General Hospital. There is no involvement of minors aged 18 years old or below. This is a "one-off" interview to be conducted in a single session, in which follow-up session is not required. Vulnerable subjects such as prisoners, children, patient with concomitant psychiatric illnesses, patients who are delirious or those without the mental capacity (both temporarily or permanently) to adequately comprehend the contents of the participant information and intent of the study as well as critically ill patients will be excluded in the study.

#### 7. What are my responsibilities when taking part in this study?

It is important that you answer all the questions asked by the study staff honestly and completely.

#### 8. What are the potential risks and side effects of being in this study?

There will not be any side effects or risks when you participate in this study.

### 9. What are the benefits of being in this study?

There may or may not be any benefits to you. Information obtained from this study will help inform the society on the impact and hence early detection and prevention in order to keep themselves healthier.

#### 10. Will the study subject be informed of the study findings?

The subject will be informed about the purpose of study as well as the process of the survey, however, the study findings will not be informed to the subject until the aggregated survey outcomes are to be shared to the public in the form of publication by obeying the publication policy stated in the protocol. Confidentiality of all patient data is ensured as patient identifiable data such as the patient's name, his/her identification card numbers (for Malaysians) and/or passport numbers will not be revealed, tabulated and reported in any form of publication. Statistical analysis and modelling approaches applied in this study will not involve patient's personal identifiable data in the Informed Consent Form (ICF) as tabulation of aggregate outcomes will only utilize data collected through the instrument (questionnaire) presented in the research protocol. The outcomes of the survey will be tabulated and reported in aggregate form only upon research purposes and cannot be identified individually.

#### 11. What is the data storage, retention and disposal policy?

All printed copies of the survey form with the raw data and informed consent form (ICF) will be kept for subsequent reference, audit and query for the next 3 years. All these documents will be destroyed and incinerated 3 years after the study completion. All electronic copies of the database will be stored in secured storage devices with password protection accessible by all researchers in this project only.

#### 12. Who is funding the research?

This study is a self-funded research.

#### 13. Can the research or my participation be terminated early?

The project leader may due to concerns for your safety, stop the study or your participation at any time. If the study is stopped early for any reason you will be informed.

#### 14. Will my medical information be kept private?

All your information obtained in this study will be kept and handled in a confidential manner, in accordance with applicable laws and/or regulations. When publishing or presenting the study results, your identity will not be revealed without your expressed consent. Individuals involved in this study and in your medical care, qualified monitors and auditors, the sponsor or its affiliates and governmental or regulatory authorities may inspect and copy your medical records, where appropriate and necessary.

### 15. Who should I call if I have questions?

If you have any questions about the study or if you think you have a study related injury and you want information about treatment, please contact the study doctor, *Dr Shirly Wong Siew Ling* at telephone number 6014-9923009

If you have any questions about your rights as a participant in this study, please contact: The Secretary, Medical Research & Ethics Committee, Ministry of Health Malaysia, at telephone number 03-2287 4032.

# Part I: Demographic Profile

1.	Gender	$\Box$ Male	□ Female
2.	Age	years	
	-	old	
3.	What is your	□ Sarawak Indigenous,	🗆 Malay
	ethnic group?	please state your ethnic	□ Chinese
		division	□ Indian
			$\Box$ Others, please
			specify:
4.	Marital status	$\Box$ Single $\Box$	□ Divorced □ Widowed
		Married	
5.	Highest level	□ No formal Schooling	□ Diploma
	of education	□ Primary Schooling	□ Bachelor's Degree
		□ Lower Secondary	□ Master's Degree
		Schooling (Form 1 -3)	□ Doctorate Degree
		□ Upper Secondary Schooling (Form 4 -6)	□ Others, please specify
			••••••

# Part II: Clinical Profile

1.	Primary cancer	□ Breast	$\Box$ Colon	
	site	□ Nasopharyngeal	$\Box$ Others, please	
		(NPC)	specify:	
		🗆 Lung		
		□ Cervical		
2.	Type of	□ Chemotherapy	□ Hormone treatment	
	treatment(s)	□ Radiotherapy	□ Bone marrow treatment	
		$\Box$ Surgical removal of	$\Box$ Others, please	
		cancer	specify:	
		$\Box$ Immunotherapy		
3.	Stage of cancer	□ Stage I	□ Stage III	
	-	□ Stage II	□ Stage IV	
4.	Do you have a	□ Yes	🗆 No	
	family history of			
	cancer you have?			
5.	How long have			
	you been	years and .	months	
	diagnosed with	5		
	cancer?			
6.	How long have			
	you completed	years and months		
	cancer	_		
	treatment?			

# Part III: Financial Impact

#### Section A: Direct Medical Costs

	Direct Medical Costs	Approx. of number of visit	Approx. cost per visit (RM)
1.	General Practitioner (GP) services		, , , , , , , , , , , , , , , , , , ,
2.	□ Treatment costs		
	□ Chemotherapy		
	□ Radiotherapy		
	□ Surgical removal of cancer		
	□ Immunotherapy		
	□ Hormone treatment		
	$\Box$ Bone marrow treatment		
	□ Palliative care		
	$\Box$ Others, please specify		
3.	$\Box$ Side effect due to cancer		
4.			
	□ Anti-ulcerants		
	□ Psychotropics		
	$\Box$ Others, please specify		
~			
5.	□ Hospitalization cost		
6.	□ Others, please specify		

### Section B: Indirect Medical Costs

	Indirect Medical Costs	Approx. of	Approx. cost per
1		number of visit	VISIL (KIVI)
1.	□ I ransportation (travel by car, airlines or		
	public transportation, parking and tolls)		
2.	$\Box$ Foods and beverage (during healthcare		
	visit or hospital stay)		
3.	□ Accommodation		
4.	□ Over-the-Counter Medications (Ex:		
	Aspirin, Antibiotic, Cough syrup, Pain		
	killer, Antifungal)		
5.	□ Complementary Medicine (Ex:		
	Nutritional Supplement, Herbal		
	Supplement, Traditional Medicine)		
6.	□ Counselling or Psychotherapy		
7.	□ Household assistance		
8.	□ Childcare expenses (if you have children)		
9.	□ Others, please specify		

# Section C: Long-term follow-up Costs

	Medical Costs	Approx. of number of visit	Approx. cost per visit (RM)
1.	□ Long-term follow up		
2.	□Late-effects management		
3.	□ Rehabilitation (help patients to return to		
	daily life and live in normal)		
4.	□ Coping		
5.	□ Others, please specify		

# Section D: Out-of-pocket Expenditure for Additional Drugs

	Addition	al Drug	Approx. of number of purchases	Approx. cost per purchase (RM)
1.	Please sp	ecify		
	i)			
2.				
	ii)			
3.				
	iii)			
4.				
	iv)			
5.				
	v)			

# Section E: Household Burden & Source of Financing Cancer Treatment

1.	Household size (Including	Please state it
	you)	
2.	Number of Dependent(s)	Please state it
3.	How much is your	RM
	household monthly income?	
4.	Which of the following	$\Box$ Savings
	sources help to reduce the	□ Family Members
	financial burden?	□ Financial Support from Organization
	*(You are allowed to select	□ Company Health Care Benefit Allowance
	more than one answer)	□ Non-Profit Organization or Charity
		$\Box$ Pension
		□ Employees Provident Fund (EPF)
		$\Box$ Redraw from retirement account (PRS)
		□ Refinancing / second mortgage on house
		$\Box$ Cash from other investments
		□ Medical insurance
		$\Box$ Borrow money from relatives or friends
		$\Box$ Selling car
		□ Selling house
		Personal bank loan
		□ Others, please specify

5.	Do any organization or non- profit organization provide financial support since diagnosis?	<ul> <li>Yes, please specify the amount withdraw:</li> <li></li> <li>No</li> </ul>
6.	Do you withdraw from your personal pension/personal retirement fund?	<ul> <li>Yes, please specify the amount withdraw:</li> <li></li> <li>No</li> </ul>
7.	Do you withdraw from your personal Employees Provident Fund (EPF)?	<ul> <li>Yes, please specify the amount withdraw:</li> <li></li> <li>No</li> </ul>

# Section F: Financial Toxicity

		Not at all	A little bit	Some- what	Quite a bit	Very much
1.	I know that I have enough money in savings, retirement, or assets to cover the costs of my treatment	0	1	2	3	4
2.	My out-of-pocket medical expenses are more than I thought they would be	0	1	2	3	4
3.	I worry about the financial problems I will have in the future as a result of my illness or treatment	0	1	2	3	4
4.	I feel I have no choice about the amount of money I spend on care	0	1	2	3	4
5.	I am frustrated that I cannot work or contribute as much as I usually do	0	1	2	3	4
6.	I am satisfied with my current financial situation	0	1	2	3	4
7.	I am able to meet my monthly expenses	0	1	2	3	4
8.	I feel financially stressed	0	1	2	3	4
9.	I am concerned about keeping my job and income, including work at home	0	1	2	3	4
10.	My cancer or treatment has reduced my satisfaction with my present financial situation	0	1	2	3	4
11.	I feel in control of my financial situation	0	1	2	3	4
12.	My illness has been a financial hardship to my family and me	0	1	2	3	4

Section G: Productivity at Work

			Employment Profile				
			Before	During	After		
Γ	1	What is your	□ Employed	□ Employed	□ Employed		
		occupational	□ Public	□ Public	□ Public		
		status?	□ Private	□ Private	□ Private		
			*Please state your	*Please state your	*Please state your		
			profession	profession	profession		
			-	-	_		
			$\Box$ Student	$\Box$ Student	$\Box$ Student		
			□ Retired	□ Retired	□ Retired		
			□ Self-employed	$\Box$ Self-employed	$\Box$ Self-employed		
			□ Unemployed	□ Unemployed	□ Unemployed		
			$\Box$ Others:	$\Box$ Others:	$\Box$ Others:		
			Please specify:	Please specify:	Please specify:		
L							
	2	Please state	RM	RM	RM		
	•	your monthly					
		income, if					
ŀ		applicable.	Absenteeism (Absent from Work Due to Illness)				
			Deferre				
┝	2		Delore	During	Alter		
	3	How many	hours	hours	hours		
	·	do you	liouis	liouis	nours		
		work?					
ŀ	4	How many					
		davs a week	davs	davs	davs		
	-	do you	·····		·····j-		
		work?					
Γ	5	Have you		$\Box$ Yes.	$\Box$ Yes.		
		missed work		I had	I had		
		because of		missed	missed		
		this illness?		days in a week.	days in a week.		
				—			
				⊔ No	⊔ No		
			Presenteeism (Los	t of Job Performance)			
ŀ	6	Have your	×	$\Box$ No (Skip to O8)	$\Box$ No (Skip to O8)		
		physical		$\Box$ Yes	$\square$ Yes		
		illness or					
		psychologica					
		l affect your					
		work					
		performance?					
		periormanee.					
		periornance					

7	How many days at work	work days	work days
	bothered by physical or psychologica l problems?		
8	On the days,	Please	Please
	you were	specify	specify
	bothered by		
	these	(Rate from 0 to 10)	(Rate from 0 to 10)
	problems,	0: Could not do	0: Could not do
	was it	anything	anything
	difficult to	10: Perform as	10: Perform as
	get work	normal	normal
	finished as		
	normally do?		
	Please rate it.		