CATASTROPHIC HEALTH EXPENDITURE AND ITS ASSOCIATED FACTORS AMONG ADULT CANCER PATIENTS IN HOSPITAL UNIVERSITI SAINS MALAYSIA

MUHAMMAD ABDUL HAFIZ BIN KAMARUL ZAMAN

UNIVERSITI SAINS MALAYSIA

2024

CATASTROPHIC HEALTH EXPENDITURE AND ITS ASSOCIATED FACTORS AMONG ADULT CANCER PATIENTS IN HOSPITAL UNIVERSITI SAINS MALAYSIA

by

MUHAMMAD ABDUL HAFIZ BIN KAMARUL ZAMAN

Research Project Report submitted in partial fulfilment

of the requirements for the degree of

Master of Public Health

June 2024

ACKNOWLEDGEMENT

بِسْمِ اللهِ الرَّحْمٰنِ الرَّحِيْمِ

In the name of ALLAH, the Most Beneficent, and the Most Merciful, Salutations be upon His Messenger Muhammad (peace be upon him), his family and his companions. With help and success granted by Allah, I have finished and completed this dissertation on time.

I am deeply indebted to my supervisor, Dr Surianti binti Sukeri, a university lecturer at the Department of Community Medicine, School of Medical Sciences, Universiti Sains Malaysia. Her unwavering support, insightful guidance, and expert knowledge were instrumental in the successful completion of this work. Her kindness and patience were a constant source of motivation and comfort throughout this journey.

I am also immensely thankful to my co-supervisor, Associate Professor Dr. Azlan bin Husin, Senior Medical Lecturer, Department of Internal Medicine, and Dr Norazlina binti Mat Nawi, Medical Lecturer, Department of Nuclear Medicine, Radiotherapy and Oncology, School of Medical Sciences, Universiti Sains Malaysia. The readiness of both committed lecturers to offer help at any time ensured a smooth process in completing this research.

To my esteemed colleagues from the Department of Community Medicine and the Department of Nuclear Medicine, Radiotherapy and Oncology, Dr Muhammad Zaim bin Mohd Samsuri and Dr Mohd Khairul Hanan bin Mohd Wajiah, Dr Suhailah binti Badaruddin, Dr Mohd Arif Saifuddin bin Sulong, Dr Aienuddin Husairi bin Husin and Dr Mohd Shafizol bin Mohamad Zuki Your support has been crucial in navigating the challenges of this project. Thank you for your unwavering assistance.

My deepest gratitude goes to my beloved wife, Zati Hananin binti Zulkarnain, and my children, Nur Hana Irdina and Ahmad Muaz. Your selflessness, understanding, and unwavering support have been the cornerstone of my strength and determination, especially during the most challenging times of this research. I am truly blessed to have you as my family.

TABLE OF CONTENTS

LIST OF TABLES

Page

LIST OF FIGURES

Page

LIST OF SYMBOLS

%	Percentage
=	Equals to
≥	Equal or more than
$	American dollar

LIST OF ABBREVIATIONS

CI	Confidence interval
COICOP	Classification of Individual Consumption according to Purpose
HREC	Human Research Ethical Committee
IQR	Interquartile range
LR	Likelihood ratio
PADU	Pengkalan Data Utama
OR	Odds ratio
RM	Ringgit Malaysia
ROC	Receiver operating characteristics
SD	Standard deviation
SDG	Sustainable developmental goal
UHC	Universal health coverage
UN	United Nation
USM	Universiti Sains Malaysia
TEH	Total health expenditure
WHO	World Health Organization

LIST OF APPENDICES

CATASTROPHIC HEALTH EXPENDITURE AND ITS ASSOCIATED FACTORS AMONG ADULT CANCER PATIENTS IN HOSPITAL UNIVERSITI SAINS MALAYSIA

ABSTRAK

Latar belakang: Perbelanjaan kesihatan kendiri (OOP) yang sangat tinggi disebabkan oleh rawatan kanser yang mahal dan penjagaan yang berpanjangan, menimbulkan risiko besar terhadap berlakunya perbelanjaan kesihatan katastrofik (CHE). Perbelanjaan kesihatan katastrofik dalam kalangan isi rumah yang terjejas oleh kanser boleh memusnahkan keluarga yang sudah menghadapi emosi dan cabaran psikologi diagnosis dan rawatan kanser.

Objektif: Kajian ini adalah bertujuan untuk menentukan proporsi CHE dan mengenal pasti faktor-faktor berkaitan dengannya dalam kalangan pesakit kanser dewasa di Hospital Universiti Sains Malaysia.

Metodologi*:* Satu kajian keratan rentas telah dijalankan melibatkan 209 pesakit kanser dewasa yang mendapatkan rawatan di wad serta Klinik Onkologi dan Hematologi, Hospital Universiti Sains Malaysia dari Disember 2023 hingga April 2024. Peserta dipilih menggunakan pensampelan rawak sistematik dan data dikumpul melalui wawancara bersemuka yang berpandukan borang soal selidik. Borang soal selidik tersebut merangkumi bahagian mengenai butiran sosiodemografi, maklumat penyakit, isi rumah, serta perbelanjaan dan pendapatan. Perbelanjaan kesihatan katastrofik didefinisikan sebagai perbelanjaan kesihatan yang tidak boleh dituntut kembali yang melebihi 10% daripada pendapatan isi rumah. Analisis regresi logistik berganda digunakan untuk mengenal pasti faktor-faktor yang berkaitan dengan CHE.

Keputusan: Kajian ini mendapati bahawa 15.3% peserta mengalami CHE. Faktor-faktor yang signifikan berkaitan dengan CHE termasuk bangsa, tahap pendidikan, status GL, dan status pekerjaan ketua isi rumah. Pesakit bukan Melayu mempunyai 6.63 kali ganda kebarangkalian untuk mengalami CHE berbanding pesakit Melayu (*p*-value=0.013, 95% CI: 1.49,29.57). Pesakit dengan pendidikan sekolah rendah mempunyai 9.56 kali ganda kebarangkalian untuk mengalami CHE berbanding mereka dengan pendidikan tinggi (*p*-value=0.005, 95% CI: 2.01,45.57). Pesakit tanpa GL adalah 4.81 kali lebih mungkin mengalami CHE berbanding mereka yang mempunyai GL (*p*-value=0.008, 95% CI: 1.51,15.34). Isi rumah yang ketuanya tidak bekerja mempunyai 6.55 kali ganda kebarangkalian untuk mengalami CHE berbanding mereka yang ketua rumahnya bekerja (*p*-value=0.014, 95% CI: 1.46,29.35).

Kesimpulan**:** Kajian ini menyoroti faktor-faktor sosiodemografi dan isi rumah yang signifikan menyumbang kepada perbelanjaan kesihatan katastrofik dalam kalangan pesakit kanser dewasa di Hospital Universiti Sains Malaysia. Penemuan ini menekankan keperluan untuk intervensi yang disasarkan bagi mengurangkan beban kewangan pada pesakit kanser, terutama yang memberi fokus kepada pendidikan, pekerjaan, dan mekanisma sokongan kewangan.

Kata Kunci: Perbelanjaan katastrofik, pesakit kanser dewasa, perbelanjaan kesihatan sendiri, perlindungan kesihatan sejagat , Hospital Universiti Sains Malaysia

CATASTROPHIC HEALTH EXPENDITURE AND ITS ASSOCIATED FACTORS AMONG ADULT CANCER PATIENTS IN HOSPITAL UNIVERSITI SAINS MALAYSIA

ABSTRACT

***Introduction*:** High out-of-pocket (OOP) health expenditures due to costly treatments and prolonged care, poses a substantial risk of catastrophic health expenditure (CHE) for households. Catastrophic health expenditure among households affected by cancer can be devastating for families already facing the emotional and psychological challenges of cancer diagnosis and treatment.

Objective: The purpose of this study was to determine the proportion of CHE and its associated factors among adult cancer patients at Hospital Universiti Sains Malaysia.

***Methodology*:** A cross-sectional study was conducted with 209 adult cancer patients at Hospital Universiti Sains Malaysia from December 2023 to April 2024. Participants were selected using systematic random sampling and data were collected through guided face-to-face interviews. The proforma used included sections on sociodemographic details, disease information, household details, and expenditure and income. The primary outcome was the proportion of patients experiencing CHE, defined as out-of-pocket (OOP) health expenses exceeding 10% of household income. Multiple logistic regression analysis was employed to identify factors associated with CHE.

***Results*:** The study revealed that 15.3% of the participants experienced CHE. Significant factors associated with CHE included ethnicity, education level, GL status, and the employment status of the household head. Non-Malay patients had 6.63 times the odds of

experiencing CHE compared to Malay patients (*p*-value=0.013, 95% CI: 1.49,29.57). Patients with primary school education or below had 9.56 times the odds of experiencing CHE compared to those with tertiary education (*p*-value=0.005, 95% CI: 2.01,45.57). Patients without GL were 4.81 times more likely to experience CHE than those with GL (*p*-value=0.008, 95% CI: 1.51,15.34). Households where the head was unemployed had 6.55 times the odds of experiencing CHE compared to those with employed heads (*p*-value=0.014, 95% CI: 1.46,29.35).

***Conclusion*:** The study highlights significant sociodemographic and household factors contributing to CHE among adult cancer patients in Hospital Universiti Sains Malaysia. These findings emphasize the need for targeted interventions to mitigate financial burdens on cancer patients, particularly focusing on education, employment, and financial support mechanisms.

***Keywords*:** Catastrophic health expenditure, adult cancer patients, out-of-pocket health expenditure, Universal health coverage, Hospital Universiti Sains Malaysia

CHAPTER 1

INTRODUCTION

1.1 Introduction

1.1.1 Out-of-pocket and catastrophic health expenditures

The World Health Organization defines out-of-pocket (OOP) health expenditures as payments made by individuals and households directly to healthcare providers at the time of service which are not reimbursed by health insurance or other financial mechanisms

(WHO, 2023). These expenditures include payments for but not limited to, medication, medical devices, procedures, and various healthcare services medical goods and services, both formal and informal, but exclude premiums paid to health insurance. High OOP health expenditures can have severe consequences for patients and households, potentially pushing them into poverty or significantly affecting their standard of living. Statistically, 97 million people were impoverished due to OOP health expenditures in 2015 (Zhang et al., 2023). Worldwide data showed that the proportion of impoverished and further impoverished due to OOP has significantly increased based on the relative poverty line, from 11.8% (752 million) in 2000 to 16.7% (1295 million) in 2019 (WHO, 2023).

High levels of OOP expenditures exceeding a certain threshold, typically 10% of total household income or 40% of non-food expenditures can indicate limited financial protection in a health system, potentially leading to financial hardship or CHE (Xu et al., 2005). Catastrophic health expenditure is a significant obstacle to achieving universal health coverage (UHC), as it can lead to financial hardship and poverty, ultimately undermining the effectiveness of healthcare systems. The significance of CHE is underscored by its designation as the indicator used to measure Target 3.8.2 of the Sustainable Development Goals towards achieving UHC by 2030. This target specifically calls for ensuring universal health service coverage without exposing households and individuals to financial risks (WHO, 2023).

The global prevalence of CHE has experienced a substantial increase from 2000 to 2019. According to recent reports, the prevalence of CHE in 2019 was approximately 13.5%, which translates to over 1.04 million individuals worldwide who faced financial hardship due to healthcare costs (WHO, 2023). This was an increase from the 9.6% prevalence in 2000, which affected almost 588 million people (Wagstaff et al., 2018). The occurrence of CHE varies between countries. The prevalence of CHE in developed nations like Sweden, the

United Kingdom, Canada, France, and Germany is reported to be relatively low and below 0.5% (Xu et al., 2003). However, the Medical Expenditure Panel Survey involving 130 million households in the US reported the prevalence of CHE was constant at 4.7% (95% CI: 3.8,5.6) in 2008 and 4.4% (95% CI: 3.6,5.3) in 2018 (Hong et al., 2022). Nevertheless, CHE was more common in less developed nations. Most individuals who experienced the CHE were from low-income nations that lacked a prepayment health financing mechanism and relied primarily on OOP compared to developed countries which applied effective health financing approaches, such as social health insurance or population-based tax-funded health systems (Garg et al., 2009).

Malaysia, a nation where the public healthcare system relies heavily on funding from taxation, recorded OOP expenditures that accounted for 35.1% of the total health expenditure in 2021 (MNHA, 2023). Nevertheless, the prevalence of CHE was minimal, amounting to about 1.5% in the year 2019 (WHO, 2023). This was attributed to the majority of the OOP expenditure occurring in the private health sector, accounting for 95.1% of the total health expenditure (MNHA, 2023). The individuals who utilised the private health sector primarily consist of individuals from higher income brackets and those who choose to participate in the private health insurance scheme, thus putting them less exposed to CHE.

1.1.2 Catastrophic health expenditure and cancer

Cancer is a collection of diseases that occur in any organ or tissue of the body. It happens when the cell grows abnormally (dysplasia) and might grow beyond the organ itself, which will invade or spread to other adjoining or distant organs (WHO, 2022). The aetiology of cancer is complex, involving genetic mutation, lifestyles that put the individual at risk for cancer (smoking, alcohol consumption, and sedentary lifestyles), and bacterial infection. Statistically, the prevalence of cancer in the world for the past five years was 50 million cases, with new cases reported around 19 million cases (WHO, 2021b). In Malaysia, for the

year 2020, the total number of newly diagnosed cancers was 48,639 patients, with breast, colorectal, and lung as the top three most common cancers (WHO, 2021a). In 2019, cancer caused up to 10 million deaths and continues to be one of the leading causes of death worldwide (Roth et al., 2018; Vos et al., 2020).

Cancer affects individuals, households, healthcare providers, the government, and stakeholders (Zhang et al., 2023). Treatments are often expensive and may not be fully covered by guarantee letter or health insurance, resulting in significant financial burdens for patient (Carrera et al., 2018). From a patient and household perspective, the economic burden of cancer comes from the direct medical and non-medical costs, and indirect costs. Direct medical cost is the formal and informal OOP payments made to obtain promotive, curative, rehabilitative, palliative, and long-term care as defined in the Classification of Individual Consumption according to Purpose (United Nations, 2018). Direct non-medical costs are the costs of transportation, food, and accommodation when seeking medical care (Hessel, 2008) . Indirect cost is the cost that patients and households face due to the inability to perform their work and loss of employment (Aminuddin et al., 2023).

Cancer treatment significantly influences the likelihood of facing CHE. Treatments such as innovative therapies, chemotherapy, surgery, radiation therapy, can all lead to high OOP and other direct non-medical expenses, which can result in financial hardship for patients and their families. A study on OOP among 189 breast cancer women receiving outpatient treatment in a tertiary teaching hospital in Kuala Lumpur reported the OOP expenses for these women were MYR 1.04 million annually comprising of adjuvant therapy (30%), traditional Chinese treatment (20.4%), chemotherapy (6.1%) and equipment and prostheses (4.6%) (Yusoff et al., 2021). In another study on the direct and indirect cost among cancer patients in Hospital Kuala Lumpur reported the mean total cost for cancer patients was MYR7955 annually (Aminuddin et al., 2023).

1.2 Problem Statement and Rationale of Study

The increasing prevalence of cancer is a significant health problem that is contributing to the alarming trend of households facing financial instability (Choi et al., 2015). Catastrophic health expenditure among households affected by cancer can be devastating for families already facing the emotional and psychological challenges of cancer diagnosis and treatment. The proportion of CHE among cancer patients in Malaysia are exceptionally high, with reported rates spanning a wide range of 47.3% to 86.5% across various studies (Azzani et al., 2017; Ting et al., 2020; Raman et al., 2022; Puteh et al., 2023). However, our knowledge on financial consequences of this specific population in the East Coast of Malaysia is noticeably lacking. Although past studies have provided insights into the proportion and factors influencing CHE in Malaysia, the majority of research on adult cancer patients were mostly concentrated in the Klang Valley region.

Adding to this lack of understanding is the presence of methodological differences in certain studies, where the estimation of OOP health spending included direct non-medical costs, resulting in an overestimation of both OOP and CHE. Therefore, addressing these methodological discrepancies and expanding the research to include geographical context such as the East Coast of Malaysia, is imperative. Addressing these research gaps is extremely important for accurately evaluating the financial difficulties faced by adult cancer patients and guiding specific initiatives aimed at reducing this burden. Examining healthcare spending patterns among several demographic cohorts and geographical areas can offer invaluable perspectives for policymakers and stakeholders. Furthermore, understanding the proportion and determinants of CHE among cancer patients informs policy and planning efforts to develop more effective health financing strategies, ensuring that healthcare systems are better equipped to address the financial needs of patients with cancer.

1.3 Research Questions

1. What is the proportion of catastrophic health expenditure among adult cancer patients in Hospital Universiti Sains Malaysia?

2. What are the associated factors that contribute to catastrophic health expenditure among adult cancer patients in Hospital Universiti Sains Malaysia?

1.4 Research Objectives

1.4.1 General objective

To study the proportion of CHE and its associated factors among adult cancer patients in Hospital Universiti Sains Malaysia.

1.4.2 Specific objective

1. To determine the proportion of CHE among adult cancer patients in Hospital Universiti Sains Malaysia.

2. To determine the associated factors of CHE among adult cancer patients in Hospital Universiti Sains Malaysia.

1.5 Research Hypothesis

There are significant factors (sociodemographic, disease and treatment, and household factors) associated with CHE among adult cancer patients in Hospital Universiti Sains Malaysia.

CHAPTER 2

LITERATURE REVIEW

The literature review was conducted using university-subscribed databases and multiple search engines available on the web, such as PubMed, Scopus, and Ebscohost. The literature search was filtered to only published materials between 2013 to 2023. Numerous searching strategies were applied, such as combining terms with Boolean operators (AND, OR, NOT). The keywords used during the search were catastrophic health expenditure, out-of-pocket health expenditure, associated factors, determinants, direct medical expenditure, and adult cancer patients.

2.1 Proportion of CHE among adult cancer patients

The proportion of CHE varies between diseases as it depends on the medication cost, inpatient and outpatient service, and treatment modality the patient needs to undergo. Cancer is one of the most common diseases that puts patients at risk of CHE (Doshmangir et al., 2020). On average, 48% of cancer patients experienced CHE a year after diagnosis (Kimman et al., 2015). The prevalence of CHE varies substantially across countries, with a disproportionately higher incidence of CHE affecting individuals in low- and middle-income nations compared to those in high-income countries (Doshmangir et al., 2021). In Malaysia, the proportion of CHE was 54.4% among adult cancer patients attending three tertiary hospitals in Klang Valley in 2022 (Puteh et al., 2023). The proportion of patients experiencing CHE varied significantly across different types of cancer, including colorectal, urological, and oral cancer, with reported rates ranging from 47.3% to 86.5% in various studies (Azzani et al., 2017; Ting et al., 2020; Liew et al., 2022; Raman et al., 2022).

2.2 Associated factors of CHE among adult cancer patients

2.2.1 Sociodemographic factors

2.2.1(a) Gender

The relationship between gender and CHE has yielded inconsistent results across various studies. A study in South Korea among households with cancer patients found no significant difference between gender and the occurrence of CHE ($p > 0.05$) (Choi et al., 2014). Similarly, a study conducted among adult cancer patients at the National Cancer Institute also showed no statistically significant association between gender and CHE ($p = 0.358$) (Puteh et al., 2024). However, a study conducted in India among COVID-19 patients who were hospitalized found a notable association. The study revealed that females were three times more likely to experience CHE compared to males (*p*-value=0.01, 95% CI: 1.31,7.30) (Garg et al., 2022) . This disparity could be attributed to gender inequality, which often leads to significant discrepancies in earnings between females and males, with women generally earning lower wages than men. However, the magnitude of disparity varies among countries (Esteban et al., 2019).

2.2.1(b) Ethnicity

A study among oral cancer patients in Oral Maxillofacial clinics in two hospitals in Malaysia found that Indian ethnicity is a predictor of CHE (AOR 6.24, p= 0.046) (Raman et al., 2022). Similarly in another study involving 630 cancer patients in three hospitals in Kuala Lumpur and Selangor found that Indian patients (69%) were more likely to experience CHE (p-value=0.015) than other ethnicities (Puteh et al., 2023). Ethnicity disparities in CHE are not limited to specific regions. A study conducted in the United States, utilising data from the Medical Expenditure Finance Survey revealed that, among the uninsured population, Non-Hispanic Black individuals (13%) and Hispanic individuals (14.2%) were more likely to experience CHE compared to Non-Hispanic White individuals (p

< 0.05), indicating a persistent and statistically significant disparity in healthcare financial burdens (Linde et al., 2024).

2.2.1(c) Age

Most studies found that older patients were at higher risk of CHE than younger cancer patients (Sun et al., 2021b; Raman et al., 2022). This disparity is largely attributed to the fact that older individuals are often less involved in economic activities, thus earning less household income (Kimman et al., 2015). However, a study in Iran showed that younger patients were three times more likely to experience CHE. This phenomenon is thought to be driven by the tendency of younger individuals to opt for private healthcare services, which were often more costly than public options (Ahmadi et al., 2021).

2.2.1(d) Marital status

Marital status is also a determinant of CHE among cancer patients. Being unmarried increased the risk of CHE for patients (OR 1.09, 95% 1.08-1.60) in Southeast Asia (Kimman et al., 2015). However, several other studies in South Korea and China showed no association between marital status and CHE (Choi et al., 2014; Sun et al., 2021a).

2.2.1(e) Education level

Educational attainment plays a significant role in determining an individual's vulnerability to financial burdens resulting from healthcare expenses. Several studies have demonstrated that lower education levels were associated with a higher likelihood of experiencing CHE compared to higher education levels (Leng et al., 2019; Puteh at el., 2023). Similar to a study done among adult cancer patients in eight Southeast Asia countries found that lower education is significantly associated with CHE (OR 1.45,95% CI 1.19-1.82) (Kimman et al., 2015). Data from the China Health and Retirement Longitudinal Study (CHARLS) over four years revealed that individuals with a primary school level or below had a higher probability of experiencing CHE (p = 0.016, AOR 1.16, 95% CI: 1.03, 1.30) (Li et al., 2023). These findings

underscore the critical role of education in determining an individual's susceptibility to financial burdens resulting from healthcare expenses.

2.2.1(f) Patient's employment status

The literature consistently highlights employment status as a crucial factor in CHE among adult cancer patients. In Malaysia, a study found that 64% of unemployed patients experienced CHE, significantly higher than other groups ($p < 0.001$) (Puteh et al., 2023). Another study in South Korea found that cancer patients who were unemployed before and after cancer diagnosis were two times more likely to experience CHE compared to employed patients (Choi et al., 2015). A similar result was seen in China, where employment was shown to be a protective factor of CHE among tuberculosis patients compared to being unemployed ($p<0.001$, AOR 0.21 95% CI: 0.09, 0.49) (Zhou et al., 2016).

2.2.1(g) Financial aid

Financial assistance reduces the likelihood of experiencing CHE by enabling beneficiaries to cover specific medical treatment costs and increase their monthly income. Despite the significance of financial aid in mitigating CHE, there remains a scarcity of research investigating the association between receiving financial aid and CHE. A single study among end-stage renal disease patients stands out in which it discovered a notable disparity between persons who had Medical Aid coverage and those who covered by national health insurance. The former group exhibited a significantly reduced percentage of individuals experiencing CHE ($p < 0.001$) (Shin et al., 2021).

2.2.1(h) Medical insurance

The relationship between medical insurance and CHE is complex and multifaceted. While some studies suggest that medical insurance can be a protective factor against CHE, others have found mixed or inconsistent results. A study in Shiraz Namazi Hospital Iran showed no significant association between having supplemental insurance with CHE among cancer

patients (*p*-value=0.32) (Kavosi et al., 2014). While in Malaysia, a study among adult cancer patients in the Klang Valley showed that 36% of cancer patients owned supplemental insurance and it was a significant determinant of CHE (AOR 3.99, 95% CI 2.31-6.90, p<0.01) (Puteh et al., 2023).

Another study found that the type of insurance is associated with CHE. In China, a study found that having Urban and Rural Residents Basic Medical Insurance (URBMI) was associated with a higher proportion of CHE (AOR 1.677, 95% CI 1.091-2.579, *p*-value=0.018) compared to Urban Employee Basic Medical Insurance (UEBMI) (Sun et al., 2021a). This finding suggests that the type of medical insurance coverage plays a crucial role in shaping the financial burden of healthcare expenses, with URBMI potentially being less effective in mitigating the risk of CHE due to lower reimbursement rates compared to UEBMI. Furthermore, supplemental insurance may help prevent patients from being at risk of CHE, but its effectiveness depends on the reimbursement conditions and coverage provided.

2.2.2 Disease and treatment factors

2.2.2(a) Type of treatment

The type of treatment also plays a role in association to CHE. In Malaysia, it was found that chemotherapy (AOR 3.7, 95% CI 2.06-6.82), radiotherapy (AOR 2.99, 95% CI 1.37-6.57), and combination of both (AOR 4.99, CI 1.48 -16.48) were the determinants of CHE (Puteh et al., 2023). In another study done among colorectal cancer patients in Universiti Malaya Medical Centre (UMMC) revealed that patients who undergone chemotherapy were three times more likely to experience CHE (Davidoff et al., 2013; Azzani et al., 2017). In America, patients on radiotherapy and antineoplastic medications were at higher risk of experiencing CHE (p<0.01) compared to chemotherapy (Davidoff et al., 2013).

2.2.2(b) Site of cancer

Various types of cancer require different treatment approaches, each with its own associated costs, which may potentially expose patients to financial hardship. However, multiple studies indicated that the specific type of cancer is not a significant predictor for CHE. A 2020 study conducted in Addis Ababa found that the type of cancer does not serve as a predictive factor for CHE (Kasahun et al., 2020). Another study conducted at the National Cancer Institute among adult cancer patients in Malaysia yielded similar findings (*p*-value= 0.413) (Puteh et al., 2024).

2.2.3 Household factors

2.2.3(a) Head of household gender

The gender of the head of household is another factor associated with CHE. Female heads of household tend to be the determinant of CHE compared to males. In Malaysia, it is a CHE determinant among colorectal cancer patients (AOR 2.91, 95% CI: 1.25-8.2, *p*-value=0.045) (Azzani et al., 2017). While in South Korea, it was similar (AOR 1.02 95% CI:1.01-1.04) among cancer patients in general (Choi et al., 2014). This is due to female heads of household receiving less salary and job opportunities compared to male counterparts (Choi et al., 2014; Zhao et al., 2016).

2.2.3(b) Head of household employment status

The association between employment status of the head of the household and CHE has been proven, as demonstrated by numerous studies. Employment was a protective factor against CHE among low-income group in Malaysia ($p< 0.01$, AOR: 0.39, 95% CI: 0.21,0.72) (Samsudin et al., 2022). In addition, a study conducted in eight Southeast Asian countries among cancer patients found that not having paid employment increases the likelihood of experiencing CHE by 30% ($p <0.05$, 95% CI: 1.11,1.56) (Kimman et al., 2015).

2.2.3(c) Presence of elderly household

The presence of elderly household members increases the likelihood for an adult cancer patient to experience CHE, as evidenced by studies done in different countries. Catastrophic health expenditure study in Malaysia (OR 3.8, 95% CI 2.6-5.6, p<0.001), Turkey (AOR 2.65, 95% CI 1.43-4.9, *p*-value=0.002) and India (OR 1.65, p<0.005) all were found to associate presence of elderly to CHE (Yardim et al., 2010; Mondal et al., 2014; Samsudin et al., 2022).

2.2.3(d) Household size

The size of the household also has a significant association to CHE. A cross-sectional study conducted among low-income individuals in Malaysia found that smaller household size was four times more likely to experience CHE compared to larger household (p<0.001, 95% CI: 2.28, 7.97) (Samsudin et al., 2022). Another study utilising data from the Health Expenditure Survey found similar results, indicating that households with smaller sizes are twice as likely to experience CHE compared to large households size (Sayuti et al., 2022).

2.2.3(e) Poverty income

Most studies showed patients in the lowest income group i.e. 1st quintile, or B40 (in Malaysia), is associated with CHE and is a predictor for it (Kimman et al., 2015; Piroozi et al., 2019; Raman et al., 2022). A study among gynecological cancer patients in the Klang Valley showed being in the high income group is a protective factor against the CHE compared to those in the low-income group (p = 0.011, 95% CI: 0.005,0.5) (Liew et al., 2022). Research conducted in Hanoi revealed that those belonging to the lowest socioeconomic group were five times more vulnerable to experiencing CHE compared to those in the highest socioeconomic group, regardless of whether they resided in slum or non-slum neighbourhoods (Kien et al., 2016).

2.2.3(f) Ownership of Guarantee Letter

Having a Guarantee Letter (GL) status is also another important factor which is associated with CHE. It can serve as a protective measure against CHE by providing financial assistance to patients. A study conducted among adult cancer patients in three different hospitals in the Klang Valley revealed compelling evidence that individuals lacking GL are nearly four times more prone to experiencing CHE compared to those who possess GL ($p< 0.001$, 95% CI: 2.06, 5.40) (Puteh et al., 2023).

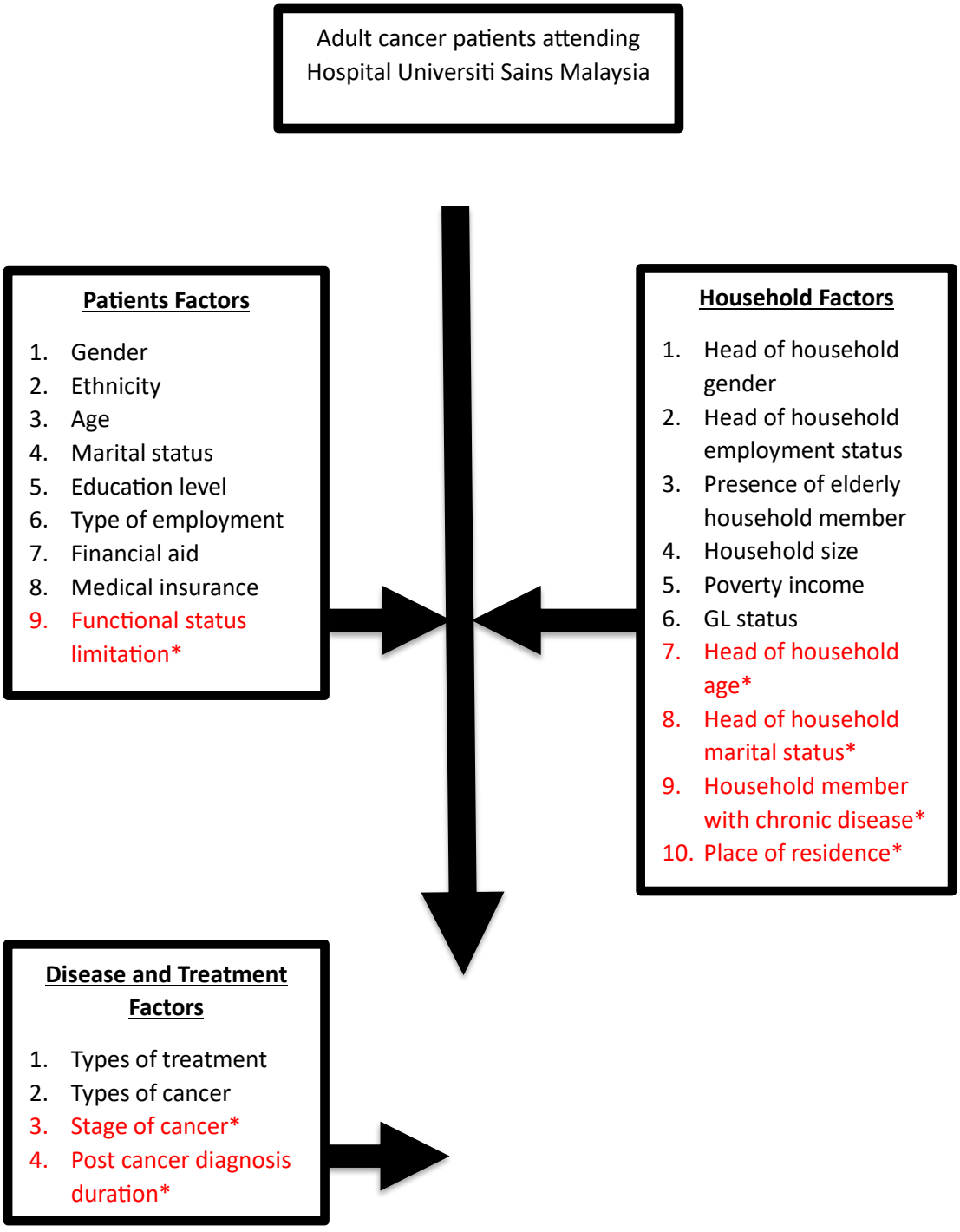
2.3 Research Gaps

Review of the literature showed that many studies on OOP health spending and CHE locally and internationally has incorporated direct non-medical costs such as transport, food and accommodation, resulting in an overestimation of both OOP and inflating the proportion of CHE. Furthermore, research on CHE among cancer patients in the east coast of Malaysia remains limited. A comprehensive review of the existing literature identified all studies have been conducted exclusively in hospitals located within the Klang Valley region. This geographical concentration suggests a significant gap in the research, as it does not account for potential variations in CHE experienced by cancer patients in other regions of Malaysia.

Moreover, there has been a notable deficiency in research examining the relationship between CHE and financial aid. Previous studies have predominantly focused on health insurance as a means of alleviating economic burdens, often overlooking the impact of financial aid. Further research is necessary to evaluate the effectiveness of financial aid in preventing the occurrence of CHE.

2.4 Conceptual framework

Based on the literature review, there were several variables that may be associated with CHE. The factors can be classified into three distinct subcategories: patients, diseases and treatments, and household variables.



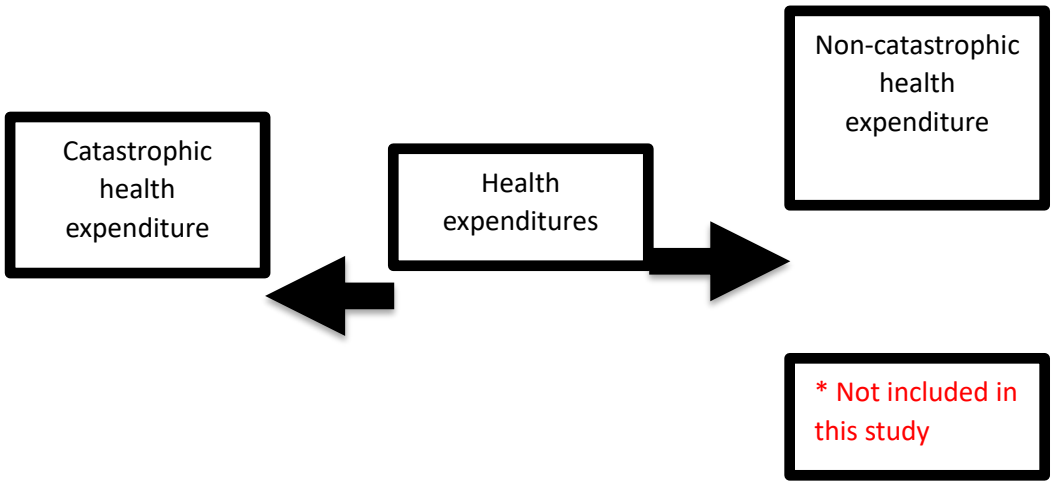


Figure 2. 1 Conceptual framework of associated factors of CHE among adult cancer patients in Hospital Universiti Sains Malaysia

CHAPTER 3

METHODOLOGY

3.1 Study design

The study design was a cross-sectional study using primary data collection among adult cancer patients in Hospital Universiti Sains Malaysia in Kelantan from December 2023 to April 2024.

3.2 Study area

The research was carried out at Hospital Universiti Sains Malaysia, a teaching hospital situated in Kubang Kerian, Kelantan. The selection was made on the basis that Hospital Universiti Sains Malaysia is the main referral centre for cancer patients in the east coast region of Malaysia.

3.3 Study population

3.3.1 Reference population

The reference population was all cancer patients in Hospital Universiti Sains Malaysia

3.3.2 Source population

The source population was all adult cancer patients from the oncology and haematology clinics and wards at the Hospital Universiti Sains Malaysia.

3.3.3 Sampling population

The sampling population was adult cancer patients from the oncology and haematology clinics and wards at the Hospital Universiti Sains Malaysia who fulfilled the study criteria during the study period.

3.4 Subject criteria

Inclusion criteria:

1. Malaysian nationality
2. Patients diagnosed with cancer for at least one year

Exclusion criteria:

1. Patients who were unable to recall health expenditures, non-medical expenditures or loss of income
2. Existing patients who defaulted medical treatment for the past one year

3.5 Sample size estimation

The sample size calculations were based on the study objectives as follows:

3.5.1 Sample size calculation (objective 1)

The sample size calculation to determine the proportion of CHE among adult cancer patients in Hospital Universiti Sains Malaysia (Objective 2) was done using the single proportion formula. Conventionally, the power of the study was set at 80 % and $Z\alpha = 1.96$, for $d = 0.05$, and the proportion of CHE among adult cancer patients was 0.86 (Raman *et al*., 2022). A sample size of 207 participants was required.

3.5.2 Sample size calculation (objective 2)

For objective 2, the PS Software for two proportion was used to estimate the sample size with:

P_0 : proportion of unexposed group that experience CHE (literature review)

P_1 : estimated probability of exposure group that experience CHE (expert opinion)

m : ratio unexposed/exposed = 1

α : 0.05

Power : 0.80

Table 3. 1 Sample Size Calculation (Objective 2)

Factors	P_0	P_1	n	m	n*m	(n*2) +10%	Reference
Age (40-65 years old)	0.62	0.80	99	1	110	220	Ahmadi et al. (2021)
Income group (B40)	0.31	0.50	104	1	104	232	Puteh et al. (2023)
Household size (1-2 person)	0.31	0.50	104	1	104	232	Rezapour et al. (2017)
Employment status (unemployed)	0.44	0.64	97	1	97	216	Puteh et al. (2023)
Education level (low level)	0.10	0.25	100	1	100	224	Puteh et al. (2023)

In conclusion, based on the above calculation, the largest sample size needed to accomplish the study objectives was obtained from the calculation of objective 2, which was 208. With the additional assumption of a 10% dropout rate, the final total number of samples required was 232.

3.6 Sampling method and subject recruitment

A systematic random sampling method was used to select patients from the oncology and haematology clinics and wards based on their clinic attendance and ward admission. The odd-numbered patients in the patients' attendance and admission lists were approached while waiting for consultation with the respective team. In the ward, patients were approached during their admission period. If a patient refused or was unavailable, the next even-numbered patient was selected. Subsequently, the sequence was resumed with the odd-numbered patients.

Patients were first screened to ensure they met the inclusion and exclusion criteria. Only patients who fulfilled the criteria were explained about this study. After patients provided their verbal approval, they were asked complete and sign the consent form.

3.7 Research tool

The research tool was a proforma developed in the Malay language and consisted of four main sections:

1. Section A: Patients sociodemographic details (8 questions)
2. Section B: Disease information (2 questions)
3. Section C: Household details (4 questions)
4. Section D: Expenditure and Income (5 questions)

Expenditures and income details in Section D were divided into direct medical costs, non-medical costs, income loss, monthly income, and fixed financial assistance. Direct medical costs were based on the definition of OOP health expenditure and was detailed based on the classification of individual consumption according to purpose (COICOP) (UN, 2019). The non-medical cost was based on the definition of additional costs for patients and

family members who accompanied the patients while seeking medical treatment, such as transportation, accommodation, and food, which were related to cancer treatment by (Hessel, 2008). Income loss was defined as salary loss of patients or family members from unemployment or daily income due to cancer (Aminuddin *et al.*, 2023). Although not essential for the estimation of CHE, data on non-medical and indirect costs were still collected and presented as supplementary context to facilitate a comprehensive discussion of the study's results in the subsequent chapters.

3.8 Operational definitions

Adult cancer patients: Individuals aged 18 and above during the interview session and was diagnosed with any cancer through histopathological test confirmation and seek treatment at the Hospital Universiti Sains Malaysia from December 2023 till April 2024.

Catastrophic health expenditure: Out-of-pocket expenses on health exceeding 10% of household income (WHO, 2023).

Out-of-pocket health expenditure: Also known as direct medical cost, OOP refers to payments made by patients or head of household (not reimbursed by third party such as insurance provider or employer) to obtain any cancer-related treatment (promotive, curative, rehabilitative, palliative, and long-term care) in the past one year. If no payment was made, it is considered as zero OOP.

Household income: Fixed and non-fixed monthly salary of every member in the households.

Education level: Categorized according to the education levels in mainstream schools and universities in Malaysia

Employment status: Categorized into four categories; 1) employed (individual who works for an employer, from the government or the private sector are considered), 2) pensioner

(individual who used to work for the government and retired from work), 3) self-employed (working individuals with no employer) and 4) unemployed (employed individuals such as the disabled, elderlies and housewives).

Ethnicity: Each person's ethnicity group is indicated on their identity card such as Malay, Chinese, and Indian. Other ethnicitys are classified as "others"

Site of cancer: The site of the primary cancer as diagnosed by the doctor (Doshmangir et al., 2021).

Household: A household is a collective of individuals, whether they are related or not, who typically live together in a shared living space and jointly contribute to the costs of sustenance and other essential needs (DOSM, 2023a).

Head of household: Household members, regardless of gender, who are seen as leaders by other members. The individual serving as the head of household must be a recipient of income and be at least 15 years old (DOSM, 2023a).

Poverty income: Household with monthly income below the poverty line index (PLI) which is at RM 2508.00 (DOSM, 2023b).

3.9 Data collection method

Data were collected using the proforma through a guided face-to-face interview session with the participants. The guided interview method ensured full completion of the proforma to prevent missing values. According to the order during the interview session, participants were assigned a unique numerical code for data entry. Each participant's interview session lasted around 15 to 20 minutes. Assistance from spouses, relatives, or caregivers was requested to aid participants who had difficulty understanding and answering the questions in the proforma. Participants who were not able to provide the

exact account of their expenditures or income were asked to give estimation values. All data obtained were entered into Microsoft Excel after each interview.

3.10 Ethical consideration

Prior to conducting the study, ethical approval was acquired from the Human Research and Ethics Committee (HREC), Universiti Sains Malaysia (study protocol code: USM/JEPeM/KK/23110864, approved on 11th December 2023). There was no conflict of interest as the researchers were not directly involved in the treatment of the subjects. Only necessary patient personal information listed in the proforma were obtained. The research team strictly asked the subjects only relevant questions based on the proforma during the interview session. The confidentiality of data was maintained at the highest level possible by combining password-protected files and password-protected computers. Only research team members were able to access the data. Data were presented as grouped data and subjects were not identified individually.

3.11 Statistical analysis

Data in Microsoft Excel has been thoroughly checked and cleaned for double or wrong entries and ensure all the data is completely entered, it is exported to and analysed using SPSS version 28. Descriptive statistics was used to summarise the socio-demographic characteristics of subjects, disease information, household details, expenditure and income. Based on their normal distribution, numerical data was presented as mean (SD) or median (IQR). Categorical data was presented as frequency (percentage).

The CHE was determined using the budget share method, i.e. monthly out-of-pocket health expenditure that surpasses 10% of the total monthly household income.